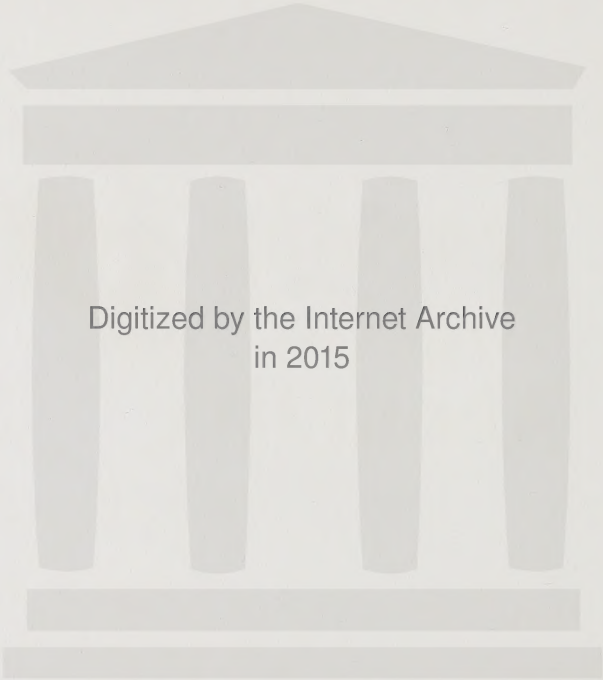
Learning Together About HIV

Alberta
HEALTH



A Resource for Caregivers and People Living with HIV

Learning Together About HIV

This project was funded by the AIDS Care and Treatment Unit under the National AIDS Contribution Program of the National AIDS Strategy Health Canada.

First Printing 1994
Second Edition and Printing 1996

This document was produced in cooperation by

Alberta Health
Provincial AIDS Program

and

Capital Health Authority
Edmonton, Alberta

Author: Penny Parker RN. BN.
Revised by Greg Ikert BA.

ISBN #077325174X

March 1996

Copies of *Learning Together About HIV* can be obtained through the:

Alberta Health
Provincial AIDS Program
ph. (403) 427-0836

AIDS Network of Edmonton Society
ph. (403) 488-5742

Learning Together about HIV is a document that has been designed to address the education needs of caregivers and persons living with HIV, and has been made possible through funding from Health Canada.

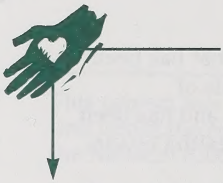
Collaboration has played a key role in the development of this document. Clinical expertise has been contributed by staff members of the Home Care Program, the University of Alberta Hospital, and the AIDS Network of Edmonton Society.

Many hours were spent by members of the Caring Together Advisory Committee, as well as Home Care and Community Health Promotion and Preventive Services staff, reviewing, editing and revising the contents. Editorial contributions were also made by the Caring Together Project Evaluators.

The essential collaborators in the development of this document have been the many people living with HIV/AIDS in Edmonton, who have given freely of their limited time to sit through interviews and share their thoughts, hopes and challenges. For far too many, their life's journey was completed prior to the printing of this document.

Everyone involved in the Project would like to take this opportunity to acknowledge the strength and inspiration of those contributors no longer with us, and continue to offer a hand in partnership to those who openly shared with us in a way that brings meaning to all that we do.

If You Are Going To Help Me



1. Please be patient while I decide if I can trust you.
2. Let me tell my story. The whole story, in my own way.
3. Please accept that whatever I have done, whatever I may do, is the best I have to offer and seemed right at the time.
4. I am not a person. I am this person, unique and special.
5. Don't judge me as right or wrong. Bad or good. I am what I am and that's all I've got.
6. Don't assume that your knowledge about me is more accurate than mine. You only know what I have told you. That's only part of me.
7. Don't ever think that you know what I should do - you don't. I may be confused, but I am still the expert about me.
8. Don't place me in a position of living up to your expectations. I have enough trouble with mine.
9. Please hear my feelings. Not just my words - accept all of them. If you can't, how can I?
10. Don't save me! I can do it myself. I knew enough to ask for help, didn't I?

Help me to help myself.

Table of Contents

"By October 2,1985, the morning Rock Hudson died, the word was familiar to almost every household in the Western world.

AIDS.

Acquired Immune Deficiency Syndrome had seemed a comfortably distant threat to most of those who had heard of it before, the misfortune of people who fit into rather distinct classes of outcasts and social pariahs... Suddenly there were children with AIDS who wanted to go to school, laborers with AIDS who wanted to work, and researchers who wanted funding, and there was a threat to public health that could no longer be ignored. Most significantly, there were the first glimmers of awareness that the future would always contain this strange new word. AIDS would become a part of North American culture and indelibly change the course of many of our lives."

HIV FACT

The World Health Organization estimates that by the turn of the century, 40 million people world-wide will be infected by HIV.

Randy Shilts. And The Band Played On: Politics, People, and the AIDS Epidemic. New York, 1987. St. Martins Press.

Introduction

When someone receives a diagnosis of HIV infection, that person begins a journey which will likely involve care and support provided by other people. Partners, friends, family members, Home Care staff and other medical personnel may all become part of an individual's personal caregiving network.

For successful "caregiving" to occur, there is an important partnership required between each caregiver and the person who is receiving care. If they commit to developing an equitable relationship that honors and supports the ability of both "partners" to contribute fully to the individual's care, the end result can be a powerful, mutually rewarding caregiving experience.

That process begins with a shared basis of factual knowledge about HIV and AIDS. When both "partners" in the caregiving relationship are operating from the same information base, the processes of communication, decision-making and caregiving/receiving become substantially more effective.

There are many sources of information available, but it takes much effort and skill to "weed" through it all to find the basics about the realities of what HIV infection means and how it may manifest itself. This document does that initial work for you. It is the result of a request from Home Care staff for a "primer" suitable for staff providing care to people living with HIV infection. As part of the larger Caring Together Federal Demonstration Project, it was developed to be used as a tool for any person providing caregiving services, and any person with HIV infection who wants to learn more about the medical and psychosocial aspects of HIV and AIDS.

This is clearly a document to be shared between the person who is the focus of caregiving efforts, and the people who are providing care and support to him or her. This gives each "partner" an opportunity to use the other as a resource for clarification and discussion. It is the hope of all those involved in this project - including the many people living with HIV and AIDS who "speak" within the pages of this document - that this dialogue will help you build stronger, more effective caregiving relationships.

A Brief Overview of HIV Infection

HIV Infection World Wide

The history of HIV infection and AIDS in North America is a relatively recent one. In June of 1981, the Centre for Disease Control (CDC) in Atlanta, Georgia, first described what was soon to be referred to as AIDS in its Morbidity and Mortality Weekly.

They described clusters of young, apparently healthy gay men in San Francisco, Los Angeles and New York who were developing a rare form of skin cancer, known as Kaposi's sarcoma (KS), that, until then, had only been seen in elderly men of black, Italian or Jewish origin.

Also identified in the young gay men was a relatively uncommon form of protozoal pneumonia, Pneumocystis carinii pneumonia (PCP) that previously had been seen almost exclusively in severely immunosuppressed individuals (people with weakened immune systems).

Although no specific cause could be found at the time, it became clear to the physicians and researchers investigating the phenomena that an underlying immune system failure was the common factor. In 1982, the name Acquired Immune Deficiency Syndrome, or AIDS, was given to the cohort of symptoms that typified the disease - weight loss, fatigue, PCP, KS and premature death. The cause was as yet unknown.

HIV FACTS

- HIV infection is a long-term chronic infection
- about half of those infected with HIV are expected to develop AIDS within 10 years
- HIV testing checks for antibodies to the virus, not for the virus itself
- it takes from 4 weeks to 6 months for the body to produce antibodies to HIV - a test "the morning after" will not give a reliable result
- HIV can infect anyone who is exposed: men, women and children
- in Africa, where HIV has been active for many years, the ratio of HIV infection is equal between men and women
- in North America, fewer women are infected with HIV than men, but the number of infected women is rising dramatically
- the best defence against HIV infection is prevention of its transmission

Initially, studies in the U.S. indicated that the risk of acquiring the syndrome appeared to be linked to having numerous sexual partners. In 1982, however, as the complex illness became more widely recognized by the medical community at large, cases were reported in heterosexual intravenous drug users, hemophiliacs, spouses and sexual partners of persons with AIDS, and children.

think about it

If you are HIV negative, imagine that you have just learned that you are HIV positive. How would you respond? What are your feelings?

Numerous sexual contacts were no longer the common denominator, nor was homosexual contact. What was emerging was a pattern of infection by a pathogen transmitted through the exchange of body fluids, especially blood and semen.

In 1984, the Human Immunodeficiency Virus (HIV) was definitively isolated, and its identification enabled the development of a test for antibodies in the blood. The antibody test made it possible to identify individuals who had been infected by HIV, and to screen donated blood and blood products to prevent transmission to transfusion recipients.

Although male homosexual and bisexual infection rates remained high in both Canada and the United States, male and female infection rates in Africa were equal, with widespread infection in the heterosexual population. Retrospective serological (blood/blood product) testing revealed that the epidemic could be traced back to the late 1950s in eastern Africa.

Although no one is sure exactly where or when HIV originated, it has been generally accepted that the human virus is related to the Simian (Green) Monkey virus. The virus first affected humans in central Africa, where the monkeys are hunted for food and often skinned and eaten raw. The monkeys also bite, increasing the potential for infection even higher.

Although initial efforts to determine the cause and the mode of transmission advanced rapidly, the

subsequent search for treatments and cures has progressed slowly. The only effective defense against HIV disease continues to be the public health effort to prevent its transmission.

HIV and AIDS in Canada

HIV infection and AIDS in Canada is thought to have had its beginning in Montreal in 1979. A male patient presented with what is now known as the classic symptoms of AIDS, although at the time it was a disease without a name or an identifiable cause. Although this man was the first known Canadian to have died of AIDS, epidemiologists are certain that there were hundreds of other Canadians carrying the virus at that time.

think about it

"Vancouver, Montreal, and Toronto account for more than 2/3 of Canada's reported AIDS cases. B.C. has the highest rate of AIDS cases, followed by Quebec and Ontario. Alberta ranks fourth in Canada." (Health Canada)

Early in 1982, the Department of Health and Welfare in Ottawa started collecting data on the number of reported AIDS cases in Canada (NOTE: this is not the same thing as the number of people who have HIV). At the end of 1982, 11 cases of AIDS had been reported in Canada. The numbers rose to 49 in 1983, tripled to 165 in 1984 and then more than doubled to 415 by the end of 1985.

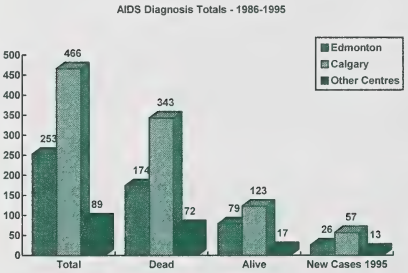
The number of AIDS cases in Canada, as in the rest of the world, climbed steadily through the '80s: in 1988, Canada reported 910 new cases. As of June 1990, 3,824 cases of AIDS had been reported in Canada. In December 1995, Health Canada reported a total of 12,670 known AIDS cases, of which 118 were pediatric (under 16 years) and 733 were adult females.

Starting in 1985, the Canadian Red Cross routinely screened all blood donations in Canada for HIV antibodies to ensure the safety of the blood supply. In

1986, the National AIDS Centre was established, and one year later, the Federal Centre for AIDS was created within the Department of National Health and Welfare.

In the early 1980s, AIDS community groups began to emerge within the gay population to provide education and support to people with HIV infection. The majority of people involved had HIV or were living with AIDS. By 1985, a national organization was formed to unite these groups, and the Canadian AIDS Society (CAS) was formed. Volunteer efforts have driven these organizations, and they are no longer identified as "gay": women, heterosexuals and senior citizens have all joined in the work of education and prevention.

AIDS Diagnosis Totals 1986-1995



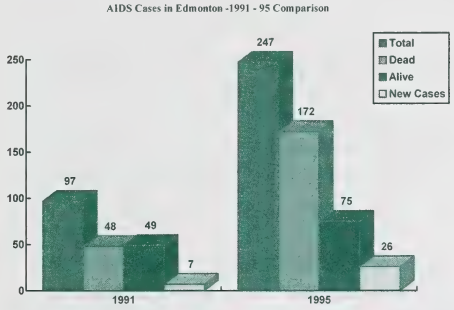
- Alberta Health (1995)

In Alberta, the first reported death from AIDS occurred in 1980. By 1984, there were 12 known Alberta cases, with 4 deaths. The numbers of newly

"A heterosexual woman returned to Canada after four years of travelling around the world. She had been sexually active and she felt that taking a test for HIV would be a good thing to do. She went to a physician and requested an HIV antibody test. The physician gave her information about the transmission routes of sharing needles and blood transfusions, then told the woman she was not part of a "risk group" and therefore did not need the test.

Two years later, the woman, who was convinced there was definitely something wrong with her health, asked another doctor for an HIV antibody test. She was again told she did not need one. She went back to this doctor a second time and insisted on having the test. She tested HIV positive. (CAS)"

diagnosed cases of AIDS in Alberta saw its biggest jump between 1988 and 1989, when the cumulative numbers climbed from 43 to 89.



AIDS Cases in Edmonton March 1991-December 1995 Comparison

- Alberta Health (1995)

By the end of January 1996, a total of 808 diagnosed cases of AIDS were reported in the Alberta AIDS Surveillance report, with 96 new cases identified in 1995. To date, 589 people have died in Alberta with a diagnosis of AIDS.

> "Another big issue regarding AIDS is not being able to plan for the future. It's hard to know what to do. Do I invest in retirement funds or do I invest in things we can do now for the next year or two years? Do I have five years or do I have 30 years? (HIV and AIDS: Canada's Blueprint Health Canada)"

Locally, there have been 253 cases of AIDS reported in Edmonton to the end of 1995, with 26 new cases reported during the last year. Two thirds (172) of the known persons with AIDS in Edmonton have died.

It is important to note that while AIDS is a reportable infectious disease in Alberta, HIV infection is not. Approximately 2,584 positive HIV antibody tests were recorded through the provincial laboratories from 1986 to the end of 1995.

THE ABC's OF HIV
(What do all those letters mean?)

HIV, CD4, KS, PCP, MAI, CMV, PML, AZT, ddC, ddI, d4t etc., etc...

Trying to understand HIV infection can seem like attempting to learn a new language; with a dictionary that is filled with abbreviations and acronyms. Most of us have heard at least some of the terms listed above and wondered "What does it all mean?"

> "Even though I assumed I was positive, when the counsellor actually sat me down and said yes, you are infected, it was devastating. (from HIV and AIDS: Canada's Blueprint Health Canada 1990)

The intent of this section of the document is to clarify the language and in so doing, clear up the misconceptions that naturally come with trying to understand a "foreign" language.

HIV stands for "Human Immunodeficiency Virus". It is a retrovirus, an organism that uses reverse transcriptase as its method of attack in the body. (Later in this section you will find a description of the process of HIV infection.)

HIV and AIDS are not interchangeable terms. HIV is the name of an infectious organism which can lead to AIDS – Acquired Immune Deficiency Syndrome. AIDS is the name of a syndrome or collection of diseases and/or infections. In some people, HIV infection is asymptomatic (shows no symptoms) for 10 years or more. These individuals are able to maintain a strong immune system and show no outward signs of illness; nor do they feel ill. But if another person engages in a risk behaviour with them, the infection can be spread to the HIV negative person. HIV infection is life-long, and there is no cure. A person who is infected will always carry the virus in his/her blood and body fluids - which is why it is so important for

> "I don't know how I got home that day. I don't know what I did. I can't remember anything. I shouldn't have driven my car. I wasn't in any state to do that. (Edmonton person living with HIV)

people who think that they may have come in contact with the virus to go for testing.

AZT, ddI, ddC, d4T, 3TC and Peptide-T are all abbreviations used to identify drugs that are designed to combat HIV infection. All are anti-retroviral medications, designed to slow the replication of HIV and delay immune system destruction.

CD4, CD8, T-cells and B-cells, gp120 and gp41, p24, etc. are all labels used to identify cells, markers and antigens that become the targets of HIV in the blood stream. Although the microbiology of the immune system can be difficult to understand, learning how HIV interferes with the body's defences gives HIV positive people and caregivers a good foundation for making health-related decisions.

HIV cannot be caught from:

- swimming pools
- washrooms
- water fountains
- telephones
- insect bites
- cutlery
- drinking glasses
- door knobs
- food
- shaking hands
- coughing
- sneezing
- hugs
- kissing

PCP, KS, CMV, MAI, MAC PML, etc. are all used to identify (and simplify the pronunciation of) opportunistic infections and AIDS related illnesses. The third section of this document will expand on these diseases, the signs and symptoms, and the medications used to treat them.

Transmission Realities

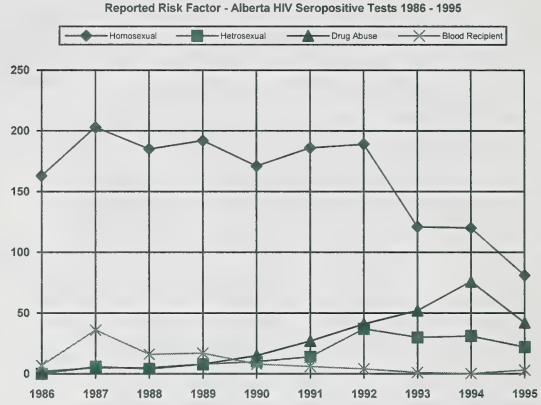
Unprotected sexual intercourse and/or sharing of injection drug needles, syringes, or equipment (i.e. spoons) with an infected individual are the two highest risk activities for acquisition of HIV infection.

The Alberta AIDS Surveillance statistics indicate that the number of persons with a newly diagnosed HIV infection who identify heterosexual contact or injection drug use as a risk factor, is increasing dramatically. Homosexual/bisexual contact remains an acknowledged risk activity, although these numbers are decreasing slightly.

Currently, world-wide statistics indicate that there is approximately 25% risk that an infant, born to an HIV infected mother, will also be infected. Breast milk is known to contain HIV in infected women, so there is also a risk of mother-to-infant transmission via breast feeding.

The decision whether or not to breast feed her infant belongs to the mother. However, breasting feeding by

Reported Risk Factor - Alberta HIV Seropositive Tests 1986-1995

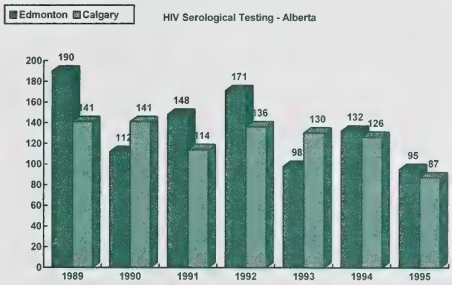


- Alberta Health (1995)

HIV positive mothers is discouraged in Canada and the United States due to the possible risk of transmission. In areas of the world where infant formulas are unavailable or where water supplies are unsafe, breast feeding is the only reasonable option for many women.

Unfortunately, for single mothers, or women on fixed or low incomes (working poor), the cost of buying formula, in addition to the other costs of raising a child, can be prohibitive. In Alberta, social services will cover the cost of formula if required by a Doctor. Also, programs like the Milk for Two program and the Food Bank may be of assistance. New mothers must be advised of the pros and cons of breast feeding and allowed to make their own informed decisions.

The HIV status of infants cannot be accurately determined until the child has reached 6 months of age in most cases. Most infant infections are due to mother-to-child transmission. Antibodies from the mother's system continue to circulate in the child's blood stream until the child develops his/her own immune system. Early diagnosis (up to six months in an asymptomatic child) is now possible using new techniques such as polymerase chain reaction (PCR) and/or viral cultures. These tests can identify nearly 100% of infected infants by six months of age, however the waiting period is often agonizing for parents.



HIV Serological Testing - Alberta

- Alberta Health (1995)

Success in preventing transmission from mother to child has been reported if the HIV positive mother starts antiretroviral therapy in the third trimester. In studies the infection rate of infants dropped from about 25% to 8 - 10%. Therefore it is extremely important to know the HIV status of the mother during pregnancy. It is recommended that all pregnant women consider taking an HIV test in their first or second trimester and if positive, weigh carefully the options when deciding on treatments and the feeding of your child.

About 20% of infants infected at birth will begin to show life-threatening symptoms due to the deterioration of their immune system during the first few

months of life. Therefore, it is extremely important that all infants born to HIV positive mothers are monitored closely in order to detect any illness.

Transmission of HIV through contaminated blood or blood products has been vastly reduced in North America. All blood donations have been screened for HIV since 1985 in Canada and the U.S. At the end of 1993, the risk of acquiring HIV infection from a transfusion was estimated to be 1 in 300,000.

Needle stick injuries are probably the route of transmission that is of greatest concern to health care workers. Although there have been hundreds of needle sticks over the last ten years, statistics show a remarkably low incidence of acquiring HIV infection (seroconversion) as a result. Currently, less than 1% of persons who have incurred a needle stick injury have become infected with HIV. Unfortunately, the number of health care workers who have acquired hepatitis from needle sticks is much higher. Therefore, the importance of not re-capping needles cannot be overstated. The use of latex gloves when handling blood and/or body fluids is also essential to avoid occupational exposure. There is an education program in place within the Home Care Program that addresses all safety rules to prevent blood exposure, called universal precautions, for those who would li' more information on this topic.

II Finding Out

HIV Testing and Counselling

For many people, the idea of going for HIV testing is extremely stressful. Not only is HIV a chronic long-term disease, it is infectious, sexually transmittable, and potentially fatal.

> "It's O.K. if you don't know all the answers. Heck, even the doctors are guessing most of the time. Be honest when you don't know something. Don't try to baffle me with bullshit... The only one you're fooling is yourself." (Edmonton person living with HIV)

Unfortunately, the benefits of early diagnosis and treatment are not so well known. Similar to other life-threatening diseases, such as cancer, early detection and treatment of HIV infection can delay the onset of symptoms and alter the course of the disease, thus improving the prognosis.

Early detection is also extremely important from the perspective of preventing transmission of the virus to others. Since an infected person may be totally symptom-free for up to ten years or longer, he or she can potentially infect others unknowingly. HIV antibody testing is the only way that people can know their status prior to developing symptoms.

Pre-test Counselling

It is essential that all persons considering HIV antibody testing be provided with counselling prior to undergoing the test. For many people, going in for HIV testing is an emotionally charged event. The aim of counselling is to help prepare for the impact of the test results, whether they are negative or positive.

Counsellors explore the rationale for testing and the implications of the results on the individual's life and/or lifestyle. The person being tested is also encouraged to examine his or her own coping skills

and support network and, if required, consider a period of counselling to help develop the necessary skills to cope with the test results.

When counselling is complete and an informed consent is obtained, the blood will be drawn and sent for testing. Alberta Health has produced a pamphlet entitled *"HIV Antibody Testing - Pre-Test Information"*, to be given to persons who are undergoing HIV testing.

> "It's really hard to ask for help. When you ask for help it's acknowledging that things are getting worse and it's not easy facing that reality. So you ask yourself, "What's better? Should I ask for help, or keep on struggling until I have no choice?" A lot of people will keep on struggling because it's too hard to accept that the virus is getting the best of you...that you're losing the battle." (Edmonton persons living with HIV)

HIV Antibody Testing

In Edmonton, there are currently four places that a person can go to for HIV antibody testing. This information may change over time. More detailed information can be obtained by calling the STD/AIDS Information Line at 1-800-772-2437 or the AIDS Network of Edmonton Society at 488-5742.

- **Sexually Transmitted Disease (STD) Clinic 427-2834**

Provides free confidential testing for all STD's including HIV. Anonymous testing, by appointment, also available **YOU DO NOT NEED** any identification nor your Alberta Health Care Insurance Number. You will be given a physical exam and pre and post test counselling.

- **University of Alberta Health Services 492-2612**

Provides free confidential testing. Located on campus, but available to the public for testing. Counselling provided.

- **University of Alberta Hospital HIV Outpatient Clinic 492-6221**

Provides free confidential testing. Located at the University Hospital. Call in advance to set up an appointment. Counselling provided.
Address is: 2nd Floor, Room 2E, U of A Hospital, Edmonton T6G 2V7

> "Knowledge about HIV/AIDS is really important. It eliminates the myths and helps people avoid making mistakes. When health care staff learn about HIV and AIDS it helps them to know what is REAL. I need my nurse to know what's real - for me, and for her."
> (Home Care client living with HIV)

• Your Family Doctor

All general practitioners are able to order the HIV antibody test. Your doctor will ask what your risk activities have been, and at present there are some doctors who will charge you a fee for the test if they do not consider it a necessary test.

Not all family doctors are familiar with pre- and post-test counselling, and you may wish to discuss your doctor's comfort with doing the necessary counselling prior to having your test done by him or her. Also, it is important to remember that your test results will become part of your permanent medical record if done out of your doctor's office.

> "I wish the doctors would consider other options, instead of blaming everything on HIV. I lost 22 pounds in about 6 weeks and my doctor couldn't figure out why. I had all the tests for HIV, and all the stomach and intestine infections. I decided to ask the nutritionist I know. She discovered that I was lactose intolerant, and showed me how to deal with it and change my diet. I was able to regain some of the weight I lost, but not all of it. I was so angry with my doctor... he just didn't look!"
> (Edmonton person living with HV)

Important note: If you require HIV antibody testing for insurance or other third party reasons, you will be charged for the test, as Alberta Health Care does not cover third party requests.

Another important note: It usually takes up to two weeks for the test results to come in. For many people, this is an agonizing time.

Post-test Counselling

Receiving HIV antibody test results is often more stressful than going in for the test, or the waiting. And the reactions to the results, whether positive or negative, are as variable and unique as the people themselves. Because this is such a stressful time, people may not remember much of what they are told at the time. Health care profes-

sionals experienced in counselling know that this is not a good time to do any teaching, and if the test result is positive, follow-up appointments can be used to reinforce teaching and answer questions.

When the test results are sent to the individual, the Provincial Laboratory also sends a copy of one of two pamphlets, *"What Does It Mean To Have A Positive HIV Antibody Test?"* or *"What Does It Mean To Have A Negative HIV Antibody Test?"*. These pamphlets are also readily available from Alberta Health, as is the larger booklet, *"HIV Antibody Testing - Information for Professionals and Experienced Volunteers"*.

It is essential that any professional or volunteer counsellor doing pre- or post-test counselling read the client pamphlets prior to giving a copy to a client, and have a good understanding of the impact of HIV antibody testing on any individual's life.

> "As a nurse I feel it my duty to care competently and compassionately for every client, regardless of their illness. When it comes to HIV/AIDS though, I feel a little frightened for my own safety... I would want to be able to talk about that with the client. I would hope that the client could understand this hesitation without reading it as rejection or condemnation."
>
> (Home Care staff nurse)

Who You Gonna Call?

The news that an HIV antibody test is positive is devastating: whether it is your own or the results of someone close to you. It is a particularly vulnerable time, and the most important first step can be the most daunting... getting help in dealing with the emotional turmoil. Like any medical "bad news", shock, denial and fear are felt almost immediately by anyone receiving a positive diagnosis.

In Edmonton, help is available from several sources. There are skilled, knowledgeable psychologists, physicians and counsellors at the University Hospital, the STD Clinic and at the AIDS Network, who have years of experience counselling in the field of HIV

infection.

It is essential that anyone who offers to provide post-test counselling be trained, non-judgmental, and sensitive to the numerous lifestyle issues that may arise.

When speaking to persons living with HIV, they often tell of the feelings of isolation and loneliness experienced when first dealing with their diagnosis. Unlike other life-threatening diseases, such as cancer, many people (especially women or those outside of the gay community) do not know anyone else who is HIV positive. Although professional counselling is extremely beneficial at this time, many persons living with HIV say how important it is to meet and talk with someone else who is living with HIV.

> "I didn't know anyone else who was positive. (Edmonton person living with HIV)"

Through the initiative of the three societies of persons living with HIV in Edmonton, and with the support of the Caring Together project, HIV positive people are being trained to act as "Peer Counsellors". These individuals participate in over 60 hours of training to become skilled listeners and counselors. They bring to the "client" their unique experience of living with HIV, and a level of empathy that an HIV negative counsellor cannot provide. They live with the virus too.

One-on-one counselling is provided on an ongoing basis as needed, and this may lead to participation in "support groups" provided by both Living Positive and the AIDS Network. The peer counsellors have also been trained to recognize their limits, and refer people on to professional counsellors/psychologists when the issues being dealt with go beyond their expertise.

Listed below are the society names and phone numbers where Peer Counsellors can be reached:

- **AIDS Network of Edmonton** 488-5742
- **Living Positive** 488-5768
- **Feather of Hope Aboriginal AIDS Prevention Society** 488-5773 (Edmonton) or 1-800-256-0459 (out of town toll free)

To Be or Not To Be...Tested

The mental anguish for many individuals living with HIV begins, not with the confirmation of the diagnosis, but with the decision to be tested. Similar to the woman who refuses to have a breast lump investigated because "it might be cancer", many people who suspect that they may have contracted HIV are fearful of finding out for sure.

Confirmation of a life-threatening diagnosis, fear of stigma, isolation from family, potential breach of confidentiality, fear of death itself, guilt associated with acquiring a disease that is transmitted sexually (whether or not that is the risk activity that they are able to identify), and the multiple losses associated with HIV disease all contribute to an individual's reluctance to be tested.

When confronted with so many potentially negative outcomes, it becomes extremely difficult to understand the positive aspects of being tested. And so, the question is often asked, "What is good about knowing that you are HIV positive?" The answers are numerous.

As with other life-threatening diseases, the uncertainty of not knowing for sure often causes more anxiety than knowing. Suspicion without confirmation is stressful and can have a negative impact on the health of an individual. For the majority, it is far better to know and to start dealing with the reality than to continue living with an unknown. For those who test HIV negative, the sense of relief is overwhelming and often brings with it a determination to

alter practices that put them at risk in the first place.

Secondly, knowing HIV status usually means living longer. Antiretroviral medications, prophylactic (preventative) therapies, treatments for opportunistic infections, and social support systems all can, and do, act to positively alter the course of HIV disease. HIV positive people are living longer, healthier lives in the 1990's than they did a decade ago and HIV infection no longer means "you're gonna die - soon!" HIV disease has become a condition that people are living with, many for ten years and more. Progression to AIDS has not occurred in all cases.

> "The difference between supportive service providers and unsupportive ones is unbelievable. When I was in the hospital, I was treated terribly. The staff made it very clear to me that I was not welcome there because I was an HIV patient. I felt like an untouchable. On the door, only on my door, were notification signs, warnings, like red flags. Someone in here has HIV." (Edmonton person living with HIV)

The knowledge that an individual is HIV positive can also have a positive impact on the way he/she lives life. Frequently, an HIV positive diagnosis leads to people addressing other illnesses - alcoholism, injection drug use, and other addictions. Healthy living becomes a priority. Many sero-positive (HIV positive) people stop smoking, focus on better nutrition and exercise habits and begin to address the negative stressors in their lives.

Both from a personal and a public health perspective, prevention of transmission is the most important factor in knowing HIV status. For the individual who is positive, this knowledge can be vitally important. Knowing HIV status can, and does lead to behavior change in many people. Practicing safer sex and not sharing injection drug equipment are the keys to reducing the spread of HIV.

As discussed earlier, comprehensive pre- and post-test counselling, addressing all of the above factors is essential whenever a person is tested for the HIV antibody.

III Immune System Basics and HIV Disease Progress

The Immune System and HIV: What Happens

The human immune system is the body's major defence against invading organisms or pathogens (bacteria, viruses, etc.). It has been compared to a nation's military force. When an infectious organism, or pathogen, attacks the body, the immune system responds with a multitude of defences aimed at destroying or immobilizing the "invader".

> "I've been HIV positive all this time but never found out until last July (1991). We never used condoms because we didn't think we needed to, so now my partner is infected too. My oldest daughter is negative, but my youngest is HIV positive... I didn't breast-feed the oldest, but I breast-fed the youngest." (Alberta person living with HIV)

Like the complex strategies of all-out warfare, the body's immune response uses an enormous arsenal of techniques to defeat the pathogen and maintain or restore health. The process is not an easy one to describe in detail, but having a basic understanding of the immune system is extremely helpful when looking at how HIV affects immune response and how people living with HIV can maintain control of their health.

The human immune system is comprised of numerous specialized cells. Most of us have heard of white blood cells. There are many different types of white blood cells, but the most important ones for consideration in this discussion are the lymphocytes and granulocytes. In many ways, these special cells are the soldiers of our body.

T-lymphocytes (T-cells)

Often, people living with HIV infection can be heard discussing their T-cell count. An increase in the number of circulating T-cells is a cause for celebration; a decrease in the count a cause for serious concern.

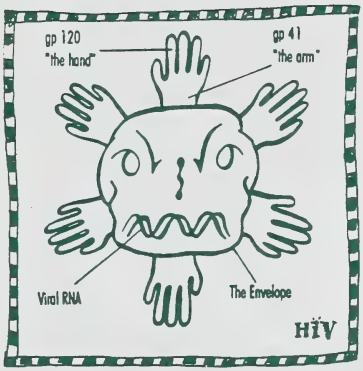
There are many different forms of T-lymphocytes, each one distinguished by a particular protein receptor on the cell's surface envelope. The two most important types of T-cells for the purposes of this discussion are the CD4 and CD8 T-cells (often referred to as simply CD4 cells and CD8 cells).

CD4 cells are, if we return to the military analogy, the field generals of the immune system. These cells are able to recognize foreign antigens, or markers, on infected cells and initiate immune response when a pathogen is present. They are the organizers and initiators of cell-mediated immunity, and the loss of CD4 cells seriously impairs the body's ability to fight off infectious organisms. HIV directly attacks CD4 cells. That is why its effects are so devastating to the immune system. Without the generals, there is no one to direct the troops.

The two functions of the CD8 cells are to destroy diseased body cells (often referred to as T-killer cells) and to turn off your immune systems attack when an infection is cleared up (known as T-suppressor cells) This ensures that healthy cells are not destroyed.

B-lymphocytes (B-cells)

The primary role of B-cells is to produce specific proteins called antibodies that bind to infected cells or individual pathogens. The antibodies either neutralize the organism or destroy the cell containing it. B-cells are activated by CD4 cells.



HIV anatomy The most important parts of HIV's anatomy are its envelope, envelope proteins, and genetic material, called viral RNA. You may recognize the envelope protein gp120 by name – it is an important player in vaccine research. Together, gp120 and gp41are known as gp160, also familiar to those following vaccine research.

How HIV binds to a CD4 cell The reason HIV infects CD4 cells – rather than, say, liver cells – is because the gp120 protein of HIV's envelope is a "mirror image" of the CD4 protein of CD4 T-lymphocytes. They fit to each other like puzzle pieces, stick together and give HIV an opportunity to invade the host CD4 cell.

The Destruction of CD4 T-cells

When the Human Immunodeficiency Virus gains access to the blood stream of an individual, the immune system responds as it would with any pathogen... it prepares to defend the body and rid it of the invader. Unfortunately, HIV has a unique way of attacking and destroying the CD4 cells that coordinate cell-mediated immune response.

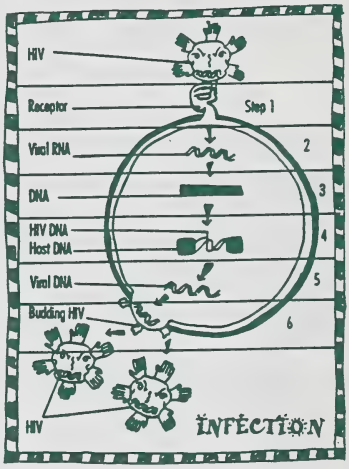
On the surface of the HIV cell is a protein called gp120. This gp120 protein and the CD4 protein on the T-cell have a strong affinity for each other, and interlock like the pieces of a puzzle. Once the virus is bound to the T-cell, another protein (gp41) from the virus imbeds itself into the cell membrane. The viral and cellular membranes meld together and the contents of the virus melts into the CD4 cell. Once the virus is inside the CD4

cell, it is able to use the host cell to reproduce. After HIV has entered into the T-cell, it releases its viral RNA (genetic material that "tells" the DNA how to make more virus) which in turn produces DNA, which is then incorporated into the cellular DNA. Since DNA contains the genetic code for replication, when the cell begins to multiply and the DNA is activated, viral copies are formed in the process. The CD4 cell replicates the virus and is destroyed itself. In short, the body actually produces more HIV.

think about it

The vast majority of new cases of HIV infection in the developed world will occur in individuals who possessed all the information they needed to prevent infection.

CD4 cells are also destroyed by the immune response itself. When the HIV locks on to the CD4 protein, the gp120 protein is displayed. CD8 (killer) cells and macrophages identify the gp120 as a foreign particle and move in to rid the body of the pathogen - destroying the CD4 cell in the process.



Countdown to reproduction Here is a simplified explanation of how HIV uses a CD4 cell to reproduce: 1) dp120 binds to CD4; 2) HIV melts into the cell wall and releases its viral RNA; 3) viral RNA produces DNA (this is the process that AZT, ddI and ddC try to interrupt); 4) cell DNA is broken and viral DNA is inserted; 5) cell begins to reproduce - DNA is activitated and viral RNA copies are formed in the process; 6) viral copies "bud out" of the cell to infect new cells.

Visuals courtesy of
POSITIVELY AWARE magazine - Winter '94

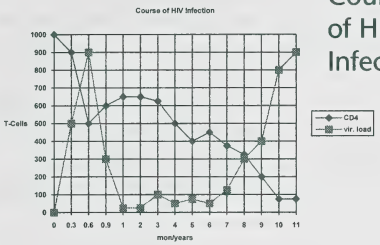
Initial Infection

When someone is initially infected with HIV, the body experiences a initial rapid decline in the CD4 count and a high level of the HIV (see graph). One may

A positive test result - finding out...

"I totally freaked out. I was not expecting that at all. They did the blood work at the end of July, and my next appointment was in September. I figured when I didn't hear from them that the test must have come back negative. But because I had the appointment already scheduled, they never bothered to call me. They just waited 'til I came in...I became hysterical and then went numb, I guess. It wasn't something I even thought about because I didn't fit the categories. You know, I don't do drugs or go to the bar, and I'm not gay. I felt safe because I didn't think I could get infected." (Edmonton person living with HIV)

exhibit flu-like symptoms (although many people have no symptoms at all) called conversion illness. The immune



Course of HIV Infection

system fights back as the healthy CD4 cells stimulate the CD8 cells to attack the virus, This causes a sharp reduction in the quantity of HIV and a substantial rise in the CD4 count, but not to levels that predated infection. Eventually, the HIV settles into the lymph nodes where it replicates slowly and quietly.

Asymptomatic Stage

Over the next seven to eleven years(possibly longer), an individual infected with HIV can lead a normal life, neither looking or feeling sick at all. A person is described as being "asymptomatic" (having no symptoms or illness due to HIV) or may have persistent generalized lymphadenopathy. Persistent Generalized Lymphadenopathy (PGL) is defined as enlarged lymph nodes involving two different sites (commonly one's neck and groin). PGL is a common feature early in HIV infection and does not seem to indicate an increased or decreased progression of HIV. It is known that people with PGL have a higher concentration of HIV in their lymph system than those who do not.

There is usually a gradual decline in the CD4 counts averaging 30 - 60 per year. This is only an average and most people do not follow along this line. It is recommended that individuals should see their doctor every 5 - 6 months for regular CD4 testing. During this period many individuals investigate and take action to ensure a healthier lifestyle. This could mean an increase in exercising, improved diet, vitamin supplementation, stress reduction, quitting smoking, reduction of alcohol and the elimination of non-prescription drugs, all which have great beneficial results to individuals living with HIV.

HIV Symptomatic and AIDS

For many persons living with HIV infection, the asymptomatic stage can and does last up to ten years and beyond. Some people do not develop AIDS, but many do.

The gradual decline of the amount of CD4 cells or the constant weakening of your immune system will usu-

The Continuum of HIV Infection

1-7 days after infection

The body's immune system tries to kill the virus, antibodies form in the blood. Flue-like symptoms develop, they disappear with 48 hours. The HIV remains.

Shortly after infection

After being infected with HIV, 95% of adults and youth will produce HIV antibodies within 3 month of infection, with the remaining by 6 months.

You must wait (see above) after each risk behavior to be sure of the HIV test results.

7-10 years after infection

The body can stay healthy for a long time with HIV. Many people live symptom-free for 7-10 years after becoming infected with HIV. This is called the **Asymptomatic stage**.

ally result in the manifestation of opportunistic infections. Opportunistic infections are described as infections caused by organisms that a competent immune response would be able to combat. When the immune defences are depleted, the opportunity is there for the infective organism to take over.

The usual CD4 count in this stage is 100 - 400. Some common complications at this stage include bacterial pneumonia, vaginal candidiasis, thrush, hairy leukoplakia, and shingles.

In May, 1986, the CDC/World Health Organization adopted a system to classify the various clinical manifestations of HIV infection. A new, revised classification system has been developed which emphasizes the importance of CD4 (T-cell) counts in the progression of HIV infection, and lists all the clinical conditions used for AIDS case definitions. Both systems are outlined in the Appendix of this document.

Symptomatic Stage

This stage lasts for 1-3 years*

The **Symptomatic Stage** of HIV is chronic and severe, including:

- general fatigue
- unexplained weight loss
- diarrhea
- yeast infections (in the mouth and vagina)
- night sweats
- thrush

AIDS Diagnosis

This stage lasts 1-3 years*

Because the virus continues to attack the immune system, the body gets weaker and weaker. The body cannot fight off illness easily and gets opportunistic infections, some of which result in an AIDS diagnosis. Examples are:

- PCP (pneumocystis carinii pneumonia) - male and female
- invasive cervical cancer - female
- Kaposi's sarcoma - male

Most people with HIV develop AIDS and eventually die (50% after 10 years). There are some people who don't develop AIDS. The reason for this is not fully understood.

* - on average

AIDS, Acquired Immune Deficiency Syndrome, is the end stage of HIV infection. As defined by the British Columbia Ministry of Health in 1993, AIDS is "a syndrome characterized by the presence of one or more diseases indicative of cellular immunodeficiency, depending on the status of laboratory evidence of HIV infection."

Simply stated, if an individual who is HIV infected develops an opportunistic infection like Pneumocystis carinii pneumonia or a cancer like Kaposi's sarcoma, he or she has developed AIDS.

Although a very few people in the world have developed what appear to be symptoms of AIDS without a

Early Warning Signs of HIV Disease Progression

(Positively Aware Magazine - Winter 1994)

Many of the symptoms below are common to a variety of illnesses. However, persistence of any of them for several weeks, especially in the absence of any other potential cause, could signal progression of HIV disease.

Entering a new phase of HIV disease can have several implications. Among them may be the need to get more frequent CD4 cell counts and other blood chemistry work-ups, or beginning prophylactic (preventative) medication that could delay or avoid the onset of certain opportunistic infections.

Diarrhea - runny bowel movements several times daily that occur repeatedly for many weeks

Cough - a dry cough lasting several days or longer, in the absence of an illness such as a cold

Fatigue - chronic tiredness during regular daily activities, despite plenty of sleep

Persistent Fever - prolonged temperature of 38.5-39.5 degrees C in the absence of an illness such as the flu

Swollen Glands - enlarged lymph glands in the neck, groin, or armpit. May be sore or tender

Night Sweats - sweats that soak the bed sheets, with or without a fever

Skin Rash - itchy bumps or ulcers appearing anywhere on the body; they often spread

Weight Loss - loss of 10 pounds or more without dieting or change in regular intake of food

Oral Problems - sores or white patches (thrush) on the gums, tongue, or palate

positive HIV antibody test, the larger scientific community continues to believe that AIDS results from the destruction of the immune response by HIV.

IV AIDS Related Illnesses

When immune defences are depleted, infectious organisms that would otherwise be held in check may have the "opportunity" to multiply and subsequently cause illnesses that a competent immune system could easily fight. Opportunistic infections, as a group, are the most common AIDS-related illnesses seen in people with HIV infection.

Several of these infections are the re-emergence of bacterial or viral infections that occurred early in life and have been suppressed by the immune system. An example of this type of opportunistic infection would be recurrent herpes zoster, the cause of chicken pox in childhood, and when re-activated, the cause of shingles in adults. Others are newly acquired infections that are the result of pathogens that we all encounter frequently in our environment (e.g. cryptococcosis, a fungus found in bird droppings and inhaled in the air we breathe).

> "What's it like to be a young man living with AIDS and house-bound? Well, I've thought about the best way to describe it; while I'm doing nothing but sitting in my wheelchair and feeling useless... for me, it's like telling a man with no legs to climb a mountain. Hopeless." (Edmonton person living with HIV)

Included in this section will be a description of some of these illnesses, their common symptoms, and an overview of their treatment. This is by no means an all-inclusive listing, but will address the more common manifestations in persons who are HIV infected. Listings have been approached from a systems perspective (respiratory, gastro-intestinal [mouth, stomach, bowel], dermatological [skin], etc.). For those who want a more in-depth discussion, please refer to the appendix and bibliography.

Respiratory Infections

Pneumocystis carinii pneumonia (PCP)

PCP is caused by a protozoan parasite, and is the most common AIDS related infection seen in the North American HIV infected population. It is the AIDS defining illness in more than 50% of persons with AIDS, and it has been estimated that up to 80% or more of all persons with AIDS will develop PCP during the course of their disease. If unrecognized or left untreated, it is life-threatening.

> "People need to hear the message right away that getting an HIV diagnosis does not mean "get ready to die" That's what I thought it meant. And I didn't see my doctor again for weeks." (Edmonton person living with HIV)

The parasite that causes PCP is a very common one in humans. Most of us have been in contact with it as pre-schoolers. The immune system controls it until there is significant destruction/ reduction of the immune response. When a person living with HIV infection has a CD4 count below 250 and develops any respiratory (breathing) difficulties, PCP is usually suspected.

> "When you have HIV, you need a support system. Changing the way you live and practicing safer sex requires a lot of support. Support from other people with HIV is important. We lift each others' spirits. Reaching out is what caring is about." (Edmonton person living with HIV)

PCP is treatable, and with antiretroviral therapy and prophylactic (preventative) medication, the first bout of PCP can often be delayed. As many as 90% of people survive their first episode of this pneumonia. Unfortunately, there are some individuals who develop PCP repeatedly, and with each infection there is more damage to the lung tissue. The resultant impaired lung function not only makes recovery from further bouts of PCP more difficult, it also can seriously reduce quality of life.

Common Symptoms

- Fever - fevers can be quite high (38.5 - 41 degrees C). May also have sweats or tremors (rigors)
- Dry, hacking non-productive cough (no phlegm or secretions)
- Shortness of breath at rest and with minor exertion. Respiratory rate may be quite high (24 - 36/min) and breathing laboured. Fingernail beds and lips may be cyanotic (bluish in color) due to poor oxygen circulation
- Increase in LDH levels

> "When I was diagnosed, the only emotion I was aware of was Anger! In 1985... an HIV diagnosis meant death. It's been almost 10 yea and I'm still here ar I'm still fighting." (Edmonton person living with HV)

Diagnosis

PCP is the most commonly looked for respiratory infection in HIV positive people. In addition to assessment of the symptoms listed above, a chest x-ray may show clear signs of a pneumonia. But, a normal chest x-ray does not exclude a diagnosis of PCP. Poor oxygen saturation should raise suspicion of PCP when combined with cough, fatigue and fever. The definitive diagnosis for PCP relies on isolation and identification of the parasite in sputum or bronchial washings. An examination called a bronchoscopy is often required to obtain proof of PCP. Bronchoscopies are invasive and often uncomfortable, and it is not uncommon for a person living with AIDS to refuse to be "scoped" when in the terminal stages of the disease process. Most have endured this procedure many times by then.

Treatment

- Dapsone in combination with trimethoprim given orally
- Bactrim/Septra - given intravenously for severe cases or orally for prevention (NOTE: Many people with HIV infection do not tolerate Bactrim/Septra (sulfa drugs) well, or develop an intolerance early on in treatment Up to 40% of individuals may suffer allergic reactions to these drugs)

- Clindamycin and Primaquine given orally
- Pentamidine - given either intravenously or aerosolized (inhaled)
- Oxygen therapy is frequently used in both home and hospital to help relieve shortness of breath, and in severe cases, treatment may be required in an intensive care unit.

> "'Support' from Home Care comes from having someone come into my home, and spend time with me because they want to be there - because they care. Don't send someone here who's only motivation is that she has a job to do and I'm just another one of her clients. That's not supportive to me at all."
> (Home Care client with HIV)

Prophylaxis (preventative therapies)

Preventative therapies are usually offered to persons living with HIV when a person's CD4 count is at or below 200, as it is at this point in the course of the disease that they become more "at risk" of developing PCP. There is a very high success rate in the prevention of PCP if prophylaxis is begun at this time.

- Bactrim/Septra - if tolerated, is the drug therapy of choice as it is extremely effective. Up to 40% of individuals may suffer allergic reactions to these drugs
- Dapsone given orally
- Pentamidine (aerosolized) - this is the least effective of these therapies and is often combined with one of the drug therapies noted above. If an individual cannot tolerate the sulfa drugs (Bactrim/Septra), aerosolized pentamidine will be given alone, or in combination with AZT (Zidovudine). AZT does not prevent PCP when given alone, but clinical trials have shown that when given in combination with aerosolized pentamidine, there are greater levels of protection from PCP, with low levels of toxicity (adverse reactions)
- Clindamycin/Primaquine orally

Bacterial Pneumonias

Pneumonia (an infection in the lung) can be caused

by a variety of bacteria in both HIV positive and negative people. In people with HIV, recurrent bacterial pneumonia (two or more bacterial pneumonia within a 12 month period) is now considered diagnostic for AIDS.

The common pathogens that often cause bacterial pneumonia in HIV positive people include strep pneumoniae, pneumococcus, and staphyloccus aureas. The tests used to diagnose these pneumonia are the same in both HIV positive and negative people. In HIV infected persons, bacterial pneumonia can occur early in the course of the diseases, but as the immune response weakens, the frequency and intensity of these infections often increases.

> "Working with persons with AIDS has taught me a great deal: not so much medically but about the process of dying with AIDS in contrast to most any other way. AIDS is merciless and unpredictable. It teases, taunts, and humiliates in a million different ways. Its result is no more horrifying or more permanent than cancer, but the roller-coaster ride it takes to death is fraught with cruel twists and obstacles." (Home Care palliative nurse)

Bacterial pneumonias are often characterized by serious symptoms that develop over a period of a few days, unlike PCP which usually takes longer to evolve. Preventative measures against bacterial pneumonia fall within the realm of "Healthy Living" - sufficient rest, good diet and exercise habits, and monitoring for symptoms.

Symptoms

- chest pain - either localized on one side or the other, or across the entire chest
- frequent productive (wet-sounding) cough with thick yellow or green sputum
- fever - gradually increasing temperature
- shortness of breath - with moderate exertion or at rest

Diagnosis

Bacterial pneumonia is diagnosed by gram, or acid fast stains and bacterial stains (sputum tests) in addition to chest x-rays.

Treatment

Early intervention with antibiotics specific to the particular organism isolated are usually successful in treating bacterial pneumonia. Pneumovax, a vaccine designed to prevent pneumococcal pneumonia is also helpful and is recommended by the Centre for Disease Control (CDC) in its guidelines for care of HIV positive individuals.

> "I have a fellow coming now from Home Care. It's actually someone who prefers to work with people who have HIV. That's made an unbelievable difference to me... It's partly what he does to help, but more important is his approach. It's... made me trust him. Now I'll let him do things I wouldn't let other people do for me." (Edmonton person with AIDS)

Other Opportunistic Lung Infections

Several other opportunistic organisms can affect the respiratory system and result in a pneumonitis. The most common of these include Cytomegalovirus (CMV), Mycobacterium Avium Complex (MAC), Toxoplamosis gondii and Cryptococcus neoformans. Since these organisms affect other organs or systems within the body with greater frequency than in the lungs, they will be discussed elsewhere in this section. Kaposi's sarcoma (a type of cancer) can also involve lung tissue.

No one expects a person living with HIV, his/her personal support network, a home care nurse or Respiratory Therapist to accurately diagnose a respiratory infection without the aid of sputum cultures or chest x-rays, but it is vitally important to watch for signs of breathing problems in all HIV positive people. All respiratory infections can develop into life-threatening events if left untreated (since they are all treatable, they should be watched for at all times.)

Tuberculosis (TB)

Tuberculosis is becoming an increasingly virulent bacterial lung infection in HIV infected individuals, as outbreaks of multi-drug resistant tuberculosis (MDR-TB) have been reported in many large North American centres. These strains pose a

threat to all immuno-compromised persons (persons with weak immune systems), health care workers and the general public, as TB is highly contagious and can be easily spread by coughing or sneezing.

Diagnosis

When a person is diagnosed HIV positive, it is recommended by most infectious disease practitioners that a TB skin test be done as soon as possible. When the CD4 count declines sufficiently, the skin test becomes insensitive and of little value. If the skin test results in a response of 5 mm or more, prophylactic (preventative) treatment with the oral medication Isoniazid is often begun.

Treatment

Treatment for active TB requires a combination of four drugs that are prescribed by the specialists at the TB Clinic. Treatment must be followed through for 9 - 12 months to ensure that the infection does not recur.

Gastro - Intestinal Diseases

HIV disease and the numerous AIDS related opportunistic infections that result from decreased immune response can affect the entire G.I. tract - from mouth lesions to diarrhea and rectal abscesses. Not only do these infections decrease the ability to eat or absorb a healthy diet, they are often painful and debilitating.

> "I hope the Home Care staff don't take my partner's bad moods personally. Between the drugs and their side-effects, the dementia and the stress of living with both of those things, he gets bitchy. His Home Care nurse brought him an African Violet because she knew that he loved plants. He swore at her and threw the plant across the room. He wasn't mad at her, but at his whole situation. He was frustrated, and she arrived at the wrong time. I hope she understood."
>
> (Partner of a person living with HIV)

Malnutrition is known to aggravate immune deficiency and has been cited as a co-factor in the progression of HIV disease. There can be any number of causes of anorexia (loss of appetite) or reluctance to eat. Abdominal cramping and pain, incessant diarrhea, mouth sores and altered taste sensation can be caused by pathogens, medications, or a

combination of both. The result is a loss of lean body mass and a depletion of fat stores. This is commonly referred to as "wasting" and can be two and a half times more common in women than in men.

> "Try and hear what your client is saying and accept it the first time it's said. We don't have the energy to argue. If I want a shower instead of a bed-bath because that's how I define dignity, please hear me and don't go on about the merits of a bed-bath."
> (Home Care client living with AIDS)

Appetite stimulating drugs such as Megace have been used with some success, and as people become more ill, total parenteral nutrition (TPN) and/or enteral (tube) feeding have been helpful with a limited number of people.

In early HIV infection, healthy eating habits and prompt treatment of gastro-intestinal (G.I.) infections are the most effective strategies used to combat malnutrition and weight loss. Later in the disease process, persons with AIDS tend to seek out high calorie, high protein diets and supplements – "fattening foods" and cholesterol levels are seldom a concern for someone living with AIDS.

Oral (mouth) Infections

Candidiasis (thrush)

Thrush is caused by a fungus or yeast known as Candida albicans. When an individual is HIV positive and develops oral candidiasis, it is often a sign of declining immune function.

Oral thrush is the most common fungal infection seen in HIV infected individuals and oesophageal (throat), vaginal and anal yeast infections are frequently endured by persons with AIDS. If unchecked, either by immune response or medications, this yeast can infect the entire gut, the lungs and airways and occasionally, get into the blood stream and cause a systemic (whole body) infection.

When a person with HIV develops oesophageal candidiasis, it is an AIDS defining infection.

> "I was in hospital for three weeks and in that time, no nurse offered to bathe me. I guess they expected my family to do it but they never told them. Finally, the day before I was discharged, my mother bathed me and washed my hair. She was so embarrassed...and so was I. She said to me that she just wasn't prepared to see me naked and wasting away. Mothers bathe and change their kids' diapers when they're babies. It's very different when that "baby" is almost 30 years old."
> (Home Care client living with AIDS)

Symptoms

- sore throat/mouth - pain with swallowing
- reddened sore areas on the tongue, palate or gums - often on the outer edges of the back of the tongue
- white patchy spots (often looks like cottage cheese)
- altered sense of taste

Diagnosis

Diagnosis is often made through visual examination by a physician and confirmed by laboratory examination (gram stain) of the yeast buds.

Treatment

Nystatin suspension (Mycostatin) - liquid that is held in the mouth for up to 5 minutes and subsequently swallowed. (NOTE: Because Nystatin suspension has a high sugar content that may encourage yeast growth and contribute to dental cavities, it may not be the drug of choice for many HIV positive people)

- Clotrimazole - tablets (troches) sucked and swallowed 4 - 5 times per day. Clotrimazole tablets are also used intra-vaginally by women
- Ketoconazole - 200 mg/day taken orally
- Fluconazole - 50mg/day or 150mg single dose taken orally. Fluconazole is often effective for resistant strains of

yeast and is used for long term prophylactic therapy
- Itraconazole - 100mg daily
- Amphoteracin B (intravenously) - only used for advanced, severe oesophageal or systemic infections
- a general reduction of all types of sugars may lessen symptoms

> "When my son was dying, I told my friends that he had cancer - don't you see? I had to. If I told them that he was gay and dying of AIDS, I wouldn't have any friends left. It's so awful to have to lie, but I need the support of friends - even under false pretences."
> (Mother of an Edmonton person with AIDS)

Herpes Simplex

There are several types of Herpes viruses that can infect humans. Herpes simplex type I and type II can cause mouth lesions, commonly called cold sores or fever blisters. Once an individual has had a cold sore, the virus remains in the body. In HIV infected people, re-activation of HSV-I or HSV-II can cause sores on the palate (roof of the mouth) gums and tongue, as well as on the lips or in the nose. If the immune system is severely damaged, HSV-I or HSV-II lesions can occur in the throat and bowel or may, in rare occasions infect the brain

Symptoms

HSV lesions have a typical appearance that is familiar to many of us. Small raised bumps or fluid-filled blisters erupt and then break and crust over. The lesions can be quite tender and are often itchy and swollen.

Diagnosis

Doctors can usually diagnose herpes simply by visual examination and this can be confirmed by laboratory culture.

Treatment

- Acyclovir (Zovirax) – an antiviral drug available in pill form or as an ointment applied directly to the lesions. Acyclovir is also available in an intravenous infusion for severe infections. Oral

acyclovir is often prescribed in advanced HIV infection for prevention of recurrence
- Foscarnet (intravenously) - used in extremely severe cases

Prophylaxis

- Acyclovir 200mg 3 to 5 times per day for frequent or severe recurrences.

Kaposi's Sarcoma (K.S.)

Kaposi's Sarcoma (K.S.) is a common malignancy (cancer) seen in persons with AIDS. It is a form of skin cancer and is frequently seen in the mouth on the palate, gums and tongue of HIV infected men (women do not seem to develop K.S. as often). K.S. lesions are bluish-purple in colour, flat or slightly raised and resemble a bruise. One or more lesions may develop, and as they increase in size they may bleed or interfere with speech and chewing. Oral K.S. lesions can be treated with localized radiation, liquid nitrogen or vinblastine (chemotherapy). If the lesions are small or not interfering with eating or speech, they may be left untreated, although closely watched.

> "Support means showing you care. Treating you as a whole person. Listening to what I say and hearing what I need... My first attempt at getting support from an agency was really devastating. I wasn't heard at all. I felt very alone and without anywhere to turn - it felt like a dead end." (Edmonton person living with HIV)

Dry Mouth

This is a common symptom in HIV disease and may be a complication of HIV itself or a side effect of drugs. This is an irritating symptom that makes chewing and swallowing difficult and can increase the risk of oral yeast infections. Thus far, the management of dry mouth consists of encouraging a high fluid diet and chewing sugar-free gum. Sucking citrus flavoured hard candies may also help. A new drug - oral pilocarpine has recently been approved for treatment of dry mouth. Check with your doctor on its availability in Canada.

Stomach/Bowel

The gut is one of the frequently affected systems in the body of an HIV infected person.

Nausea, vomiting, anorexia (loss of appetite), altered taste sensation, abdominal pain and cramping and diarrhea may be experienced in varying degrees throughout the course of HIV disease.

The causative organisms can be viral, bacterial, fungal or protozoal. In cases where no other pathogen is found, HIV itself is thought to be targeting the gut. Maintaining body weight can be an ongoing struggle.

> "When they're standing around his bed and talking about him instead of to him, it's hard to believe that the intent is to CARE." (Partner of an Edmonton person living with HIV)

The first step in diagnosing gastro-intestinal (gut) infections is by stool specimens, and this is clearly the least invasive method. If stool analysis yields inconclusive results, more invasive and uncomfortable procedures (gastroscopy, colonoscopy) may be necessary.
Both the infections and the examinations are uncomfortable and negatively impact quality of life for people with AIDS. Early diagnosis and prompt treatment are often successful in relieving symptoms.

Mycobacterium Avium Complex (MAC)

MAC is a mycobacterial infection caused by two organisms - mycobacterium avium (a pathogen found in bird droppings) and mycobacterium intracellularae (found in household dust, soil and water). Like many other opportunistic infections, we have all been exposed to these normally occurring environmental pathogens

In HIV infected individuals, MAC reactivates when the damage to the immune system is extensive (CD4 count less than 100). MAC is an AIDS defining illness. MAC tends to be a systemic infection, found in blood cultures as well as stool specimens, but can take up

to 6 weeks to grow in culture to confirm the diagnosis. These bacteria are often resistant to antibiotics and require a multi-drug approach to treatment. For some individuals, medication side effects are difficult to endure.

> "I'd like to ask Home Care staff to be up front and honest. Advise your client and his/her caregiver about all the services that are available. Offer the services you think are needed, but don't insist... it can be perceived as questioning the abilities of our own caregiver. We need that trust relationship to remain intact; to be supported, not questioned." (Edmonton person living with HIV)

Some sources suggest that MAC is responsible, at least in part, for the progressive wasting (loss of weight) seen in many people with AIDS.

Symptoms

- fever - with or without night sweats
- fatigue - low energy levels and weakness
- diarrhea - frequent liquid stools with abdominal pain
- wasting - unwanted weight loss without dieting/ poor appetite

Diagnosis

- stool and blood cultures - these can take up to 6 weeks to produce results
- direct biopsy of bowel tissue

Treatment

- multi-drug treatment is required. Currently, one of the preferred regimes includes:
  - Ciproflaxin
  - Ethambutol
  - Rifampin
  - Clofazamine
- Clarithromycin, Rifabutin and Amikacin may also be used

In people with a CD4 count of 100 or less, Rifabutin may be given prophylactically.

Cryptosporidiosis

One of the nastiest parasites to take up residence in the gut is Cryptosporidium, which lives in farm animals and is passed to humans via water or food contaminated by animal feces. This organism causes profound diarrhea that can result in severe dehydration and electrolyte (blood chemical) imbalance. It can contribute to weight loss and malnutrition and, when severe, often results in hospitalization for fluid and electrolyte replacement. Intravenous fluid replacement may also be required at home.

> "I've got everything planned for after I die; I need you to help me plan for how I'm gonna die...that's what I need you for"
>
> (Edmonton person living with HIV)

Symptoms

- massive watery diarrhea - up to 20 or more episodes daily
- abdominal cramping and gas pains
- dehydration
- weight loss

Diagnosis

- stool specimens are tested for ova and parasites and several specimens may be required before the parasitic cyst is isolated

Treatment

- Azithromycin and Paromomycin - with limited success
- high fluid intake to avoid dehydration
- anti-diarrheals, such as Lomotil or Immodium
- Acetaminophen - may be helpful in relieving cramps

Cytomegalovirus (CMV)

CMV is a type of herpes virus and is very common in Western cultures. Many of us are infected in early childhood. CMV can easily be spread from person to person via mucus contact (kissing, sexually) or through blood and body fluids.

The most common site of CMV infection in HIV infected people is in the retina (discussed later in this section). In the gut, CMV infects the colon, causing CMV colonitis (inflammation of the colon) which results in abdominal discomfort, weight loss and diarrhea.

Symptoms

- diarrhea - frequent liquid stools
- abdominal pain and cramping

> "It's so hard knowing that I could potentially pass on my fatal disease to the person I love...simply by making love! So we don't. And that's pretty awful for two people who are young and in love." (Edmonton person living with AIDS.)

Diagnosis

- CMV colonitis is definitively diagnosed on biopsy obtained via sigmoid or colonoscopy. This is an uncomfortable invasive procedure, but it is necessary for accurate diagnosis.

Treatment

CMV is treated with one of two intravenous medications that can be delivered either in a hospital day ward or at home.

- Gancyclovir (DHPG) - intravenous infusion
- Foscarnet - intravenous infusion

High dose oral Acyclovir may be recommended to prevent CMV in persons with severely reduced immune function - CD4 count less than 100.

Kaposi's Sarcoma (K.S.)

As discussed in an earlier section, K.S. is a type of skin cancer that can occur in the G.I. tract. When it occurs in the stomach or bowel it can cause pain, nausea and vomiting and a feeling of fullness after only a small amount has been eaten (early saity). A variety of types of chemotherapy including vincristine, vinblastine and bleomycin have been used to treat this cancer.

Dermatologic (Skin) Conditions

People with HIV develop numerous skin conditions. Some are relatively benign and easily treatable while others, like Kaposi's sarcoma, can be disfiguring and debilitating. But, no matter how simple the skin condition may appear to be, its emergence should be acknowledged as a possible sign of decreasing immune function and should be followed up closely.

Seborrheic dematitis, psoriasis and folliculitis are common and treatable with topical steriods, ultra-violet light (PUVA) and antibiotics.

Genital warts (human papilloma virus or HPV) are viral infections and may be more difficult to deal with. HPV in women is especially problematic if the cervix is infected, as it sometimes leads to cervical cancer. HPV can be diagnosed through a pap smear. Many therapies, including laser treatments are recommended to treat this viral sexually transmitted disease (STD).

Warts on other parts of the skin (also caused by types of HPV) may be difficult to treat and can recur.

Molluscum contagiosum, a bumpy wart-like condition can occur genitally and on the face. Although liquid nitrogen may be initially effective, the lesions often recur.

> "Every four hours I'm reminded that I am dying... My pill box beeps, I take my AZT, and know that a day will come when this stuff won't work anymore and I'll be on my way out. It's hard living with the "threat of illness" and the certainty of death." (Edmonton person living with HIV)

Herpes Simplex I & II

HSV-I and HSV-II can cause lesions in and around the mouth (as discussed previously). Both viruses can also cause genital lesions on the penis, vulva, vagina, perineum and anal skin.

Treatment is most commonly oral acyclovir and is

often successful in controlling lesions. On occasion HSV does not respond to acyclovir. Should this occur, it is important to consult a specialist.

Herpes Zoster (Shingles)

Varicella zoster virus (VZV) is the virus that causes chicken pox in children and then becomes dormant in the body. When the immune response deteriorates, the virus re-emerges and is the cause of shingles. Shingles is an extremely painful condition in which the virus follows the nerve pathways from the spinal cord across the abdomen, the back or the arm. In HIV positive people, the lesions can become large, crusted and extremely painful. Herpes zoster frequently occurs early in the course of HIV infection and is often a harbinger of increasing immune system failure.

If VZV affects the 5th facial nerve it can result in damage to the cornea of the eye on the affected side, and an opthamologist should be consulted.

> "I know rationally that I can't go home to B.C. again, to walk in the forest or sit and watch the birds on the lake...but, if I accept it in my heart, then I lose all hope. Without that hope, there's nothing left to live for." (Edmonton person living with HIV)

Post-herpetic neuralgia (nerve pain) can be a severe problem and may require the expertise of a pain specialist to control it. Tricyclic antidepressants and Zostrix cream have proven to be helpful.

Symptoms

- painful watery blisters that follow nerve pathways

Diagnosis

- VZV is diagnosed by visual examination by a physician

Treatment

- Acylovir - topical, oral or in severe cases, intravenously
- Foscarnet - may be needed for treatment of persistent lesions

Kaposi's Sarcoma (K.S.)

As noted earlier, K.S. is a common malignancy (cancer) found in a person with HIV infection. K.S. is more likely to appear in HIV positive gay or bisexual men than in other HIV positive populations, and there is some speculation that a sexually transmitted infection component is involved.

K.S. lesions are a cancer of the connective tissue and are similar to bruises in appearance, but do not blanch (turn white) when pressure is applied. The lesions can be solitary or multiple, flat or raised, progress slowly or rapidly. K.S. needs to be monitored closely, and if it spreads to the internal organs or is associated with edema (swelling) or ulcerations, this indicates that immune function is severely compromised. K.S. lesions in the lungs or stomach can be fatal.

Symptoms

- blue-purple skin blotches, single or multiple that increase in size and number
- as with any cancer, K.S. can cause fatigue, weight loss and mild fever

> "Every day I wake up wondering what it will be next. I'm almost blind and nothing tastes right because of the thrush. Wiggling my toes hurts and I've got diarrhea again! I think cancer would be so much easier. (Edmonton person with HIV)"

Diagnosis

- K.S. is diagnosed by visual inspection followed by biopsy to confirm

Treatment

- chemotherapy - vincristine, vinblastine, bleomycin (NOTE: Chemotherapy can cause severe nausea and vomiting. Antiemetics (anti-nausea drugs) such as Zofran are extremely helpful in controlling these side-effects)
- Alpha-interferon - with or without AZT
- radiation therapy

47

Decubitus Ulcers (Pressure Sores/Bed Sores)

Anyone who is malnourished, losing weight and fatigued (low energy/ tired) has the potential to develop pressure areas. Monitoring skin integrity, especially over bony prominences (hips, knees, shoulders, ankles, heels, ears) is essential for a person with AIDS. Any redness in these areas that does not resolve within 20 minutes of repositioning is cause for concern. Additional padding (cushions, spenco bed or chair pads, sheepskin pads) should be used on all chairs and beds and if an open area develops, nursing management with appropriate dressings is essential.

> "I've been told by two different doctors in two different areas of practice that I'm dying and that I should "get used to it". I have to accept it, but...I don't know how to. If if do accept it, then what? How will things change for me? I'm 29 years old, and I'm so scared." (Edmonton person living with HIV)

In terminal phases of AIDS, when the individual is bed-ridden, re-positioning a small amount approximately every twenty minutes is a priority to preserve the skin integrity and prevent existing pressure areas from worsening. Adequate pain management helps reduce the discomfort experienced with frequent repositioning.

Other Neoplasms (Cancers)

Lymphoma, a cancer that affects the lymphatic system, is becoming increasingly common in persons with AIDS. Since the lymph system travels throughout the body, lymphomas can be found in the gut, bone marrow, internal organs or the central nervous system. Although non-Hodgkin's lymphoma is the most frequently seen, Hodgkin's and Burkitts lymphomas also impact persons with AIDS. Primary central nervous system (CNS) lymphoma is also seen, although this is rare.

Lymphoma is a life-threatening AIDS related malignancy and is usually seen in late-stage disease. It is characterized by enlarged lymph nodes (glands in the neck, groin, arm pits), weight loss and low-grade fever with or without night sweats.

Chemotherapy, radiation therapy and alpha-interferon may be helpful to slow the progress of the cancer, but seldom halt the spread of the disease. Expert palliative care to control pain and symptoms is needed for the person with advanced lymphoma.

> "I don't need an AIDS expert to be my Home Care nurse, but she has to know the basics so that she can understand what's happening to me. And I need someone who is willing to leave their judgements at the door and treat me like any other client on her caseload." (Edmonton person living with HIV)

The Eye

The eye is the target of numerous opportunistic diseases in persons living with HIV infection. Kaposi's Sarcoma, cryptococcus, herpes (simplex and zoster) and HIV itself may all, at some point during the course of the disease, affect the eye and reduce visual acuity (ability to see).

By far, the most commonly encountered eye infection is cytomegalovirus (CMV) retinitis. Persons with HIV infection and a CD4 count less than 100 - 150 are at risk to develop CMV retinitis. Regular eye examinations every one to six months are recommended to facilitate early detection, and any newly developing visual problems should be checked by an opthamologist as soon as they arise. CMV attacks the tissue of the retina and, if left untreated, will quickly destroy the retinal attachment and lead to total loss of vision in the affected eye. Prompt retinal re-attachment has been successful in restoring vision for some people. Retinal detachment is a clinical emergency and must be attended to immediately.

Symptoms

- floaters - fuzzy grey spots in the visual field
- tunnel vision
- blurred vision

Diagnosis

CMV is diagnosed by direct opthamologic exam by an eye specialist.

Treatment

- Gancyclovir (intravenously)
- Foscarnet (intravenously)
- Retinal re-attachment

Treatment for CMV retinitis is life-long and discontinued only if blindness is complete or adverse medical side effects develop. Intravenous therapy is initiated in hospital and continued on a daily basis at home or in day ward.

(NOTE: The Canadian National Institute for the Blind (CNIB) is an extremely helpful resource for people with CMV retinitis and their caregivers. Their phone number is 488-4871.)

Neurological (Nervous System) Manifestations

Neurological complications in persons living with HIV infection can be the result of numerous causes. Opportunistic infections, medications, cancers and HIV itself can all impact the brain, spinal cord and central nervous system.

Meningitis

Studies indicate that 30 - 40% of persons with AIDS will experience neurological problems of varying degrees. Of the opportunistic infections, toxoplasmosis, cytomegalovirus and herpes can all affect the brain and result in inflammation of the membranes that cover the brain.

think about it

We continue to work in an environment which still strongly stigmatizes people with HIV infection and, rather less strongly, people who are involved with AIDS care and education. Unhappily, AIDS and HIV disease are still so strongly bound together with gay issues that the public at large cannot separate the two strands. (Health and Welfare Canada, 1992)

Symptoms

- headache - constant
- stiff neck
- fever
- personality changes, confusion
- seizures and coma if unrecognized

Treatment

• Toxoplamosis	Clindamycin Azithromycin Pyrimethomine
• Cytomegalovirus	Gancyclovir (DHPG) Foscarnet

Peripheral Neuropathy

Neuropathy is the term used to describe any disease of the peripheral nerves, or those that control movement and sensation.

In persons living with HIV infection/AIDS, peripheral neuropathy is thought to be caused by HIV itself or

can be a side effect of drugs - especially ddI, D4T and ddC. Neuropathic (nerve) pain has become one of the most difficult and frustrating complications of HIV infection to treat.

Symptoms

- burning or tingling sensation - feet, lower legs and hands
- numbness - feet and lower legs

Treatment

- tricyclic anti-depressants, e.g. Elavil
- seizure medications
- acupuncture
- narcotics - with limited success

> "People need to be followed up even if they say they don't need something right now. When a person says "I'm not ready now", it doesn't mean they want to be dropped like a hot potato. Keeping in contact means you care. It shouldn't be coercive but it keeps the communication open, so I feel that when I am ready, there's someone there for me." (Edmonton person living with HIV)

Progressive Multifocal Leukoencephalopathy (PML)

PML is a brain disorder caused by the JC papovavirus. Most adults were exposed to the JC virus early in life and developed a natural immunity to it. JC virus attacks the myelin (protective covering) of the nerve fibres and gradually destroys the covering over time. PML infection occurs in less than 5% of persons with AIDS.

Symptoms

- headache, double vision
- memory loss/ difficulty thinking
- speech problems
- difficulty walking/ poor coordination
- progresses to coma

Diagnosis

PML is diagnosed by CAT scan or MRI scan. A biopsy of brain tissue is needed to confirm the diagnosis.

Treatment

Currently, there is no effective treatment for PML, although AZT may cause clinical improvement. Symptom management and palliative care are required.

AIDS Dementia Complex (ADC)

ADC has become one of the most difficult complications to manage in HIV positive people. Mental deterioration leading to memory loss, confusion and deteriorating intellect can be the result of infections, stroke, vitamin deficiency, medications, substance abuse, and probably HIV itself. Most people with advanced, severe ADC do have HIV in the brain.

> "I'm so lucky! I have my home, good friends and I'm able to take care of myself. I don't think about dying - I don't want my luck to run out." (Edmonton person living with HIV)

Since there is as yet no specific test for HIV dementia, it is a diagnosis of exclusion after all other causes have been ruled out.

If HIV is determined to be the cause of dementia, treatment is supportive, although AZT has proven to be helpful in reducing symptoms of ADC and may prolong life. Losing the ability to remember and think clearly is, without question, the most significant loss experienced by people with AIDS. Most persons with AIDS deny the reality of these problems when they begin. It is "the thing we dread the most", devastating to the person with AIDS, and his or her friends and family.

ADC may progress from mild memory loss and inability to concentrate, through to a comatose, mute and incontinent (inability to control bodily functions) state.

Care and management of ADC parallels that of other dementias and there are excellent resource books available, such as *"The 36-Hour Day"*. Other resources and publications are listed in the appendix.

V Health Interventions

Anti-Retroviral (HIV) Drugs

AZT, ddI, ddC, d4T, 3TC...alphabet soup. Not only do the opportunistic infections that can potentially affect an individual who is HIV positive come in a colorful array of acronyms and monikers, so do the anti-retroviral medications...the drugs that directly combat HIV.

There has been much controversy regarding anti-HIV drugs over the years, and there is still much uncertainty. But within the last year there have been some remarkable and promising developments in this area of study. This section will review some of the new developments that has occurred including: when to start treatment, Monotherapy v.s. Combination therapy, 3TC & AZT, Viral Loads, and Protease Inhibitors.

When to Start Treatment

An individual may feel that their individual "healing" regime starts the the day they receive their positive diagnosis. The term healing is used in terms of mind, body and spirit. While this section mainly deals with the body aspect of healing, specifically with medical treatment, the other aspects of healing are found in other sections of this book and various different resources (The Resource Centre of your nearest AIDS Organization is a good place to start looking).

Soon after you receive your diagnosis, your doctor will want to do a CD4 count and other different lab tests. What the physician is trying to do is to get a snapshot of where your immune system is at that moment. Since you have just undergone considerable stress (stress amongst other things can lower your CD4 count) and CD4 tests have a very large variance - meaning any one test may not give a accurate picture, the doctor will want you to come back in a month or two to repeat the test.

CD4 counts range any where from 600 - 1200. A consistent count of between 400 - 500 should spur you into thinking about medical therapy and starting discussions with your doctor on this issue. If your count is higher, but you are beginning to not feel well, you should also talk to your doctor. Up to the end of 1995, the standard treatment was AZT monotherapy (only taking one drug) and there was allot of controversy about whether one should start taking it because AZT was very toxic, it had a lot of bad side effects and its usefulness was in question. Today many things have changed.

Monotherapy vs. Combination Therapy

Though several years of study, doctors have determined that two or more drugs are more effective than one when it comes to treating HIV. This is mainly because of HIV's ability to mutate and replicate so quickly that it was able to build up resistance to drugs in a short period of time. The evidence was so strong that combination therapy has become the norm. The best combination to date involves a newly approved drug called 3TC and an old one - AZT. Together these drugs fight HIV better than any single drug or combination to date and has been approved as a combination for initial treatment of HIV Infection. The effect is that this combination increases CD4 counts but more importantly decreases the amount of the virus you have in your body. 3TC and AZT is one of the best toleralted HIV therapies currently available. The most commonly reported adverse side effects were: headaches, nausea, fatigue and diarrhea. Talk more to your doctor and call your nearest AIDS Service Organization to get more detailed information.

Viral Load

A new approach is currently being studied to treat HIV. Until recently, researchers have been relying on your CD4 count to determine the effectiveness of drug

therapy. While this seemed to have its benefits, the huge variance of CD4 tests compelled researchers to find a better way to determine the effects of HIV on your body and a drug's effect on HIV. This "better" way was to actually measure the amount of HIV in your body - this measurement is called your viral load. Researchers now have developed an accurate test that determines your viral load called the quanatative PCR RNA test. All HIV drug trials are now being evaluated on the ability to increase your CD4 count as well as to lower your viral load. Unfortunately, at this time, the viral load test is not available to your doctor because of costs (about $300.00/ test) but look for it soon to be as common as a CD4 count test. With both of these tests in use, an extremely accurate "snapshot" of your immune system and the progression of HIV will be available.

Protease Inhibitors

AZT, ddI, ddC, d4T, and 3TC are known as nucleoside analogues reverse transcriptase inhibitors. A new class of drugs called protease inhibitors are showing promising results in clinical trials.

Nucleoside analogues work by mimicking one of the naturally occurring building blocks of the DNA in the cell, interfering with the ability of HIV to reproduce itself. This interference occurs just as the HIV is entering the cell. Protease inhibitors, on the other hand, work a a later stage in the viral life cycle, after the virus has successfully infected the cell and is attempting to make new copies of itself.

To date, saquinavir is the most widely studied protease inhibitor. Early results from U.S. and European studies of varying doses of saquinavir given alone and in combination have shown a modest increase in CD4 cells and a decrease in the amount of the virus in the blood. Best results have been seen with triple combinations.

"I was talking to someone about living with AIDS and he kept going back to my homosexuality. Finally I couldn't take it any more and said to him, "Why can't you get your mind out of my crotch?" I am a person who loves and lives with another person. We've been together for over 8 years. We're no different than any other couple - we share the housework and argue about whose turn it is to take out the garbage. We love each other other - the only thing that is different from heterosexual couples is the way we express that love physically. Why is that the only thing that's important to you." (Edmonton person with AIDS)

Two other protease inhibitors are also presently being studied: ritonavir and invirase. These have demonstrated a remarkably consistent benefit for suppression of HIV in trials. With ritonavir, two independent clinical trials have shown decreased viral loads and lead to the highest sustained increase in CD4 counts yet associated with a single antiretroviral drug. Both of these drugs however do have significant side effects that need to be considered before they are approved. Look for these drugs to be in trials throughout 1996 and approved in Canada sometime in 1997 if results continue to be positive.

In summary, the questions HIV+ individuals asked themselves have shifted from three years ago to today. When should I start taking drugs has remained consistent but if I should take drugs has changed. Combination therapy has shown to be effective and the side effects manageable and more developments are just around the corner. It is extremely important that all HIV+ individuals talk with their doctors and educate themselves about drug therapies.

Defensive Eating

(Positively Aware Magazine Winter 1994)

Eating can be one of life's great sins, but eating raw or improperly prepared foods could be a mortal sin for people with very advanced HIV disease, who are at greater risk for food-borne illnesses. Among these illnesses are botulism and salmonellosis, which can cause severe diarrhea.

A food-safety strategy, or "defensive eating", can help reduce chances of food poisoning. Some tips:

- *Buy only pasteurized milk and eggs in the shell.*
- *Don't chop raw vegetables with the same knives*

and cutting boards you've just used to cut raw meats.

- *Avoid thawing frozen foods at room temperature. Instead, thaw them in the refrigerator, in the microwave, or under cold running water.*
- *Double wrap meats and store on low fridge shelves.*
- *Don't keep leftovers for more than three days.*
- *Avoid raw eggs, which are often used in home-made mayonnaise, eggnog, and in some fresh restaurant salad dressings (Caesar salad dressing), and desserts.*
- *Ask for a fresh container of cream in restaurants that leave them on tables throughout the day.*
- *Avoid raw shellfish or rare meat and poultry.*

helpful video

"Healthy Eating Makes a Difference" is a resource book and video for people living with HIV. It is available on loan from the AIDS Network or the Public Health Services resource office.

Defensive eating is not paranoid eating. Food-borne illnesses account for a small fraction of AIDS-related illnesses. But prevention plays a part in that.

VI HIV Infection in Women and Children

Women and HIV Infection

In the early years of the HIV epidemic, it was thought that HIV infection only happened to men who had sex with other men. We know now that HIV does not discriminate and that a heterosexual woman engaging in high risk activities is as likely to become infected with HIV as a gay male. There is no known sexually transmitted disease that affects only one sex... and 75% of HIV cases result from sexual transmission.

> "Many of us are in relationships with partners who do not respect us. This makes it difficult to insist that our partners use a condom. It also makes it difficult to refuse sexual activities that put us at risk for contracting HIV. If we fear violence when we assert our right to protect our health, we are even further limited from protecting ourselves. For the woman in an abusive relationship, the risk of becoming infected is a silent, invisible and deadly form of abuse." (from Edmonton Women and AIDS Project, 1993)

There is no question that adult males make up the majority of cases of AIDS, but there is an alarming increase in the number of HIV positive women and children world-wide. Early in the AIDS epidemic, it was recognized that women in Africa were being infected at the same rate as men: the demographics of the infection in sub-Saharan Africa are 40% men, 40% women, and 20% infant/child. In North America, the focus of AIDS research, education and prevention was the adult gay or bisexual male. Women were not considered.

It has been estimated by the World Health Organization more than three million women and well over one million children around the world that are HIV positive. In addition, the number of AIDS orphans world-wide is estimated to be well over one million. Officials in New

York have projected that by the year 1997, there will be 80,000 AIDS orphans in the Burroughs (Bronx) area in New York City alone. Currently, in North America, **AIDS related disease is the 4th highest cause of death in women of child-bearing years. It is the 7th highest cause of death in adolescents, and the 2nd highest cause of death in men in their 30's.**

> "Some people think that I'm promiscuous. I don't agree. When they start punching you in the face, you leave, and hope you do better the next time. Everyone has a different definition of promiscuous - and their definition is usually "one more sexual contact than they have had". I was infected by my second husband and I didn't find out that he was positive until after he died."
>
> (Edmonton person living with HIV)

In the early years of HIV in North America, clinical trials and medical research was focused on men. In the mid-eighties, when it began to be recognized that women were becoming infected, they were, for the most part, excluded from clinical trials. The rationale given at the time was that women might become pregnant during the drug trial and the drugs could potentially harm the fetus. The result of excluding women from research and clinical investigation has been that many women have died of AIDS related illnesses unnecessarily - some not even knowing their diagnosis.

Knowledge about the effects of HIV on women's bodies is still haphazard, and, unfortunately, women are still being misdiagnosed. At the present time, there are still physicians in the Edmonton area who do not feel that HIV antibody testing is necessary for women who are not "promiscuous" or injection drug users. Women are being refused testing by their family doctors or are being told that they must pay for the test, since it is not considered medically necessary. Ongoing physician education is a must if this situation is to change.

In many ways, women are disenfranchised in our society. There are important related issues that impact many women living with HIV infection: lower incomes, poor housing, unemployment, single parenting, lack of child support, and feelings of powerlessness around all these issues.

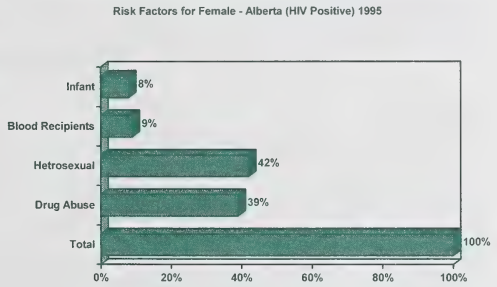
> "I don't worry about me nearly as much as I worry about my kids. I'm a single mother and when I die, who's gonna raise them? My parents aren't able to take them, they're old. And their father doesn't live here anymore and he's the one who gave it (HIV) to me! It's their future that haunts me - not my own. (Edmonton person living with HIV)"

For single mothers, or women in abusive relationships, HIV infection is just one more crisis that they deal with, and the knowledge that HIV is a long term chronic infection reduces its importance in their lives. Feeding their children today is much more important than their potential poor health years down the road.

Much of the literature relating to women and HIV infection, or women and AIDS, suggests that women tend to die earlier in the course of their disease than men do. The mean survival rates for women that have been published indicate a much faster progression from asymptomatic HIV positive to an AIDS defining illness and, subsequently, an earlier death from an AIDS related illness.

Although there are some disease characteristics that are unique to women as a result of anatomy (reproductive organs etc.), nothing has been found that indicates that the virus attacks women more vigorously than it does men. What is known, is that women go undiagnosed or misdiagnosed longer than men do.

Risk Factors for Female - Alberta (HIV Positive)



If a woman is diagnosed later in the course of the infection, she is not able to take advantage of the medications (i.e. AZT and 3TC) that slow the progression of the virus and alter the course of the disease.

The early clinical presentation of HIV is only slightly different in women than it is in men; and the time from initial infection to the development of symptoms is thought to be the same for both sexes. Many of the early symptoms of HIV infection that men experience also happen in women, i.e. diarrhea, weight loss and fatigue.

There are noticeable differences in how the disease progresses however, and, so far, there is little understanding of why these differences occur.

Women rarely develop Kaposi's sarcoma, the cancerous skin lesions seen in men, and it appears that women tend to have more breathing difficulties and frequent pneumonias. The most noticeable differences in how HIV presents in women occur in the reproductive organs. Pelvic infections, cancer of the cervix and vaginal yeast infections are often seen in HIV positive women and can be difficult to treat.

Candidiasis

The same yeast organism that causes thrush in men, causes vaginal (inside the vagina) yeast infections in women. Many women who do not have HIV infection develop vaginal yeast infections. In women who are HIV positive though, these yeast infections are often difficult to treat, cause a lot of itching and swelling, and come back month after month.

Symptoms include white, curdy vaginal discharge, severe itchiness, and/or red, raw tissue at the opening of the vagina and the surrounding area.

Candidiasis is diagnosed by laboratory examination of a swab taken from the infected area. Treatment include Mycostatin-based ointments and vaginal

suppositories, nystatin ketoconazole. If conventional treatments do not relieve symptoms, Flucanozole given orally (150 mg given once every two - four weeks) may prevent recurrence. It is also extremely important that sexual partners be treated as well.

> "I didn't think there was any need for us to use condoms. I believed I was in a committed relationship because I had been with my husband for four years. We had two children together... I trusted him. Then he went out and had an affair with someone who was infected. I was pregnant with my son when my husband infected me. He put me and his children at risk just because he wanted to get laid." (Edmonton person living with HIV)

Pelvic Inflammatory Disease (PID)

PID is the term used to describe an infection in the reproductive system of a woman. PID is most often caused by the sexually transmitted diseases gonorrhea or chlamydia.

Inflammation in the fallopian tubes, ovaries and uterus, often accompanied by pain in the lower abdomen and a purulent (bad smelling) vaginal discharge are the classic signs of PID. For many women who are HIV positive, PID is severe and painful, often requiring admission to hospital to diagnose and treat the infection. Scarring of the fallopian tubes can make it impossible for some women to have children. As with vaginal yeast infections, PID occurs in women who are not HIV postive, but the symptoms are more difficult to treat when HIV has weakened the immune system.

Cervical Lesions and Cancers

Medical research has shown that there is direct link between a condition known as human papilloma virus (HPV) and cancer of the cervix. HIV infects the skin on the sex organs of both males and females. HPV can cause warts to grow and HPV can cause cancers of the genitals (vulva, vagina, penis, cervix). For women who are HIV positive there is an increased risk for HPV to cause cancers to develop on the genitals. A PAP test should be done every six months on HIV positive women so that early diagnosis and possible

treatment of the warts can occur. Since there is a direct causative link between HPV and cancer of the cervix, regular PAP smears can also be used for early detection of abnormal cervical cells that indicate early cancer in this area.

Studies have shown that women who are HIV positive are at greater risk to develop cervical cancers and that these cancers are more difficult to treat, are more extensive and indicate a poorer prognosis (shorter time left to live) than the same conditions in women who are HIV negative. Treatments for these cancers are often immunosuppressive (reduce the strength of the immune system) and not recommended for people who already have a compromised immune response. In January of 1993, the CDC added invasive cervical cancer to the list of AIDS defining illnesses in HIV positive persons. This is the first uniquely female AIDS diagnosis.

Pregnancy and HIV Infection

For many women, having children is extremely important. Being HIV positive doesn't change that need. There is no current evidence indicating that pregnancy accelerates the course of HIV infection in women who are positive or that they progress more quickly to an AIDS defining disease if they have had a baby since becoming infected with the virus.

Vertical transmission (spread of the virus from mother to child) has been documented in the medical literature since the mid '80s. Until recently, in North America, it was commonly accepted that there was a 25% risk of an HIV positive

> "When you hear the stories of how kids like Ryan White were treated it makes it really hard to have the courage to talk about a young child I know here in Edmonton who is HIV positive. His blood reports aren't so good any more though. I don't know what his caregivers are going to do when he's too sick to go to school...other kids can be so cruel, and I don't think most of the teachers would be very supportive either. I know they've talked about lying and saying it's leukemia, but they also know that by doing that, they would be reinforcing in this little guy that what he REALLY has is something bad... so bad that it can't be talked about. And to a kid that age, does having something that bad also mean that he's bad? I don't know."

woman having a baby who was also infected. This meant that an HIV positive pregnant woman had about a one in four chance of passing her infection on to her fetus.

A clinical trial just completed in the United States has shown that in women with a CD4 count over 200 who were given AZT during the second and third trimesters of their pregnancies, and intravenously during delivery, the mother-to-fetus transmission rate was dramatically reduced, to approximately 8%

Although the effectiveness of AZT has been in question over the years, there seems to be clear-cut evidence that it is an effective medication in the prevention of vertical transmission of HIV. It should be cautioned that the long term side-effects of AZT on the infant and mother are as yet unknown.

> "I wish people could understand that HIV is a virus, and that they have no right to judge sick people on the basis of their disease." (Edmonton person living with HIV)

HIV Infection in Infants and Children

HIV infection in infants and children (paediatrics) represents a small but growing segment of the total number of infections. At the present time in North America, cases of HIV infection in youngsters makes up 1% of all reported cases of AIDS.

Some infants may have acquired HIV from the breast milk of HIV positive women, and there are children who became infected via transfusions prior to 1985. The large majority – between 80-90% of all HIV positive infants and young children – were infected either in utero (before birth) or at the time of birth. Recent studies indicate that there is no significant difference in the rate of infection between infants delivered vaginally or via Ceasarian section.

Since the majority of new cases of HIV infection in youngsters occur as a result of transmission from the infant's mother, it is important to monitor all infants born to HIV positive women closely.

If an infant is considered "at risk", there are tests that can be done to diagnose HIV status within the first months of life, but because HIV in infants is relatively rare in Canada, these infants should be referred to a paediatric AIDS specialist to have the tests done.

Once a child reaches 6 months of age, HIV tests - either antibody, PCR or viral or a combination of all three can be used to determine HIV status. By 15 months, the child will have developed his/her own immune system and has eliminated the maternal (mother's) antibodies that were carried in the blood stream since birth.

> "Sometimes I want to curl up in a ball in the corner and never come out, but I don't have that luxury. I have two little kids who need me."
> (Edmonton person living with HIV)

If a child born to an HIV positive mother develops an AIDS defining infection or malignancy, it can be presumed that the child is HIV positive, even in the absence of a definitive test result.

There appears to be a much shorter symptom-free (asymptomatic) stage in infants infected with HIV than there is in adults. Currently, less than 30% of all infants infected with HIV will develop AIDS within the first six to twelve months of life, and for these babies, life is short. In the other 70% AIDS commonly develops before the age of ten. Many children live to 10-12 years of age.

In children who have a definitive diagnosis of HIV infection, guidelines have been established for initiation of anti-retroviral therapy dependent on CD4 cell counts. These criteria differ dependent upon the age of the child, as normal CD4 counts start out quite high and gradually decrease with age, until the adult range is reached in early adolescence.

In addition to the CD4 count criteria for initiating anti-retroviral therapy, children are also considered for therapy if they present with an AIDS defining illness, failure to thrive, HIV associated malignancy, recurrent

septicemia or meningitis, or abnormalities in their platelet count.

Since PCP risk is very high in HIV positive children, careful monitoring of CD4 count and respiratory status is essential. Recurrent otitis media (ear infection) is another extremely common infection found in HIV positive children. Standard antibiotic therapies are usually effective in treating the infection.

> "The toughest thing has been knowing I'm not going to see my kids grow up. I still can't deal with that. Seeing them graduate from high school, get married, go into a career or whatever, have their own kids... to know I'll never see that is really difficult to deal with. It makes it so much harder because when you're a mother, your kids are everything to you. This virus takes all that away from me because someone else will be mothering them."
>
> (Edmonton person living with HIV)

Another common finding in HIV infected children is developmental delays or not meeting the "milestones" of normal growth and development. These babies often do not grow or develop the mental capacities expected as they move through the formative years; some never sit up, play with toys, or make attempts at speech. For those who do survive to preschool age, Early Intervention programs and programs for developmentally delayed children are the most appropriate placements, if available.

All children who are HIV positive should be considered for immunizations against the common childhood infections, just as children not infected with HIV are. The one major difference being that HIV positive children should NOT be given live vaccines, such as the oral polio vaccine or BCG. MMR (mumps, measles, rubella) can and should be given as long as there are no signs of diminished immune function.

Recent studies have indicated that intravenous immunoglobulin given to HIV positive children with CD4 counts greater than 200 is useful in the

prevention of recurrent bacterial infections like otitis media. These children should receive DPT (diphtheria, pertussis, tetanus) vaccine and often benefit from receiving a yearly influenza (flu) vaccine.

Children with AIDS do not often develop the malignancies (cancers) that adults do, and seldom present with CMV (cytomegalovirus) or toxoplasmosis. Much more common are the bacterial infections and a respiratory disease called Lymphoid interstitial pneumonitis (LIP). As mentioned earlier, PCP is also common in children with AIDS. Treatments and preventative therapies for children with AIDS are complex and best left to the direction of a paediatric infectious diseases specialist.

HIV infection in an infant or a child is a family disease, and requires a multidisciplinary team approach to best help deal with the multiple challenges encountered by both the child and his/her parents. In the vast majority of these cases, there is at least one other family member who is HIV positive or has AIDS. In some families, both parents are HIV positive, and/or, more than one child is infected. The phenomenal challenges and losses experienced by these families requires intervention beyond that provided solely by a physician.

VII Psychosocial Impact of HIV Disease

The story below was contained in a photo-essay published in Life magazine in early Spring of 1994.

"What we want people to think about is to be careful with what they do because this isn't just an infection, it's your life. Things get worse as you go along with this disease, but if you do contract it, let me say to you, it is not the end. It just makes everything a little more precious.

I have a family that is all HIV positive. My wife and I used I.V. drugs and quit two and a half years before our child, Amy, was born. She is 21 months old and is infected. We found out two months after her birth. What a pain it is to look at this beautiful little girl and know you could lose her at any time."

The man who gave the interview above lost his wife to an AIDS related disease shortly after the interview. For many of us, it is incomprehensible that an entire family could be HIV positive, yet it can and does happen...and not only in places like New York or Montreal. ***It can happen here.***

Living with HIV disease is not easy. The physical challenges posed by the virus itself and the infections that emerge as the immune system fails are numerous, debilitating and unpredictable. The long term effects of living with these challenges is extremely stressful - not only physically, but psychologically.

> "These people (HIV positive) really own their disease by the time they are referred to Home Care. They've lived with it for a long time and have been able to define what aspect of their illness is the most important to them. Some are really into nutrition, others are really conscientious about their prophylactic medications. We have to acknowledge this in these clients and really try to develop a partnership with them - work with them on what they identify as important...not what we think is. That's really different from working with other palliative clients, who usually look to us to identify the important things."
> (Edmonton Home Care Nurse)

The stress of living with HIV disease is not simply the stress of living with a chronic life-threatening condition. It is the stress of living with a disease that is stigmatized by our society. The link between HIV and persons and activities that are considered undesirable or unacceptable remains in the minds of many people.

Like syphillis, and to some extent alcoholism, moral meaning has been attached to this physical condition. And it is the stigma of HIV disease that has the most negative impact on the lives of many persons living with HIV.

In her work, AIDS and its Metaphors, Susan Sontang writes, "Getting cancer...is sometimes understood as the fault of someone who has indulged in "unsafe" behaviour - the alcoholic with cancer of the oesophagus, the smoker with lung cancer: punishment for living unhealthy lives. But the unsafe habits associated with cancer...are the result of weakness of the will or a lack of prudence, or of addiction to legal (albeit very dangerous) chemicals. The unsafe behaviour that produces AIDS is judged to be more than just weakness. It is (considered) an indulgence, delinquency - addictions to chemicals that are illegal and to sex regarded as deviant."

According to Health Canada, in its publication, *Ending the Isolation*, "Because of the social stigma

associated with HIV, infected individuals are often denied the comfort and support society otherwise gives to those who are seriously ill. The extreme stress of HIV disease has produced hitherto unseen levels of denial, distress, anxiety, anger, guilt, disruption and confusion."

In the 1980s, when HIV infection was first identified on this continent, people who belonged to specified "groups" were seen as the only ones "at risk" for contracting the disease. Homosexual men were the first to be identified, followed by injection drug users and immigrants from countries where the disease was considered endemic. The majority of cases occurred in gay men, and the disease was initially named Gay Related Immune Disease (GRID). At the time, the belief that this illness only struck men who had sex with other men seemed the natural conclusion.

> "AIDS, like other fatal diseases, is about aloneness - aloneness now and the fear of an eternity of aloneness. We must confront this fact unblinkingly."
> (Ending the Isolation)

We are now well into the second decade of the epidemic of HIV disease in North America, and the reality that HIV is a virus that is transmitted via blood and blood products, and is sexually transmitted (both homosexually and heterosexually), is well documented scientifically. And yet, in the minds of many people, the stigma attached to HIV disease and its relationship to the people considered to be on the "margins" of society (gay men, injection drug users, sex trade workers) remains. The recent, and dramatic, increase in the number of HIV positive people who identify heterosexual activity as the route of transmission has done little to shift the old perceptions to the new reality: HIV can happen to anyone.

The terminology applied to those people infected via blood/blood product transfusions or through mother to infant transmission, the "innocent victims", implies that those who became infected via sexual or injection drug routes, are guilty of acquiring the virus.

Compassion, or the lack thereof, is often dictated by how a person became ill - not by the reality that they are ill.

Multiple Loss

To date in Edmonton, as in the rest of Canada, the majority of persons living with HIV and AIDS are homosexual (gay) men. The losses experienced by individuals who identify as gay, and their community as a whole, have been monumental over the last decade and a half. For many in the gay community, HIV and AIDS has become synonymous with "multiple loss".

> "This disease is unique - there's nothing else like it! It's not just one condition, but a series of one thing after another. The course of the disease is so unpredictable, and these clients are all so young. It's really not the same as cancer." (Palliative Home Care Staff)

For some gay men, diagnosis of HIV infection has meant disclosure of their homosexuality to parents and other family members, which has resulted in condemnation and exclusion from their families of origin.

In an article entitled AIDS: Observations of a Hospital Chaplain, written by Douglas Graydon, and published in the Journal of Palliative Care in 1988, the author speaks to this isolation and loss of family: "At a time of great vulnerability, the patient is often challenged by family and friends to justify and defend issues of acceptance, sexual behaviour, and moral responsibility. While in greatest need of nurturing and support, the patient can experience instead the trauma of alienation because of fear and ignorance of homosexuality, and of illness and death. The patient, who has had to deal with rejection and alienation from society because of sexual orientation most of his life, now confronts these issues again with little or no control over them."

Thus, individuals with HIV disease not only have to confront all the losses associated with life-threatening illness; loss of future, career, body image and comfort, quality of life and social interaction, loss of future...

they often must deal with loss of family. This has also been true for gay persons who have identified a family of choice - friends or lovers within their community whom they have adopted, in the absence of a supportive family of origin. It is not unusual to hear gay men talk of losing ten to fifteen close friends over a period of five years. They have watched as the people they spend Christmas with, their bowling team, and the people they vacation with, have all died.

> "I have the opportunity to model for others that there is NO threat is caring for AIDS clients. I don't know any other way to help to normalize this disease and the people it affects. Caring for them the same way that I care for other clients is how I advocate for people with AIDS. If I can do it, anyone can. (Edmonton Home Care Staff)

In addition to the losses mentioned above, there is one loss that in many ways is unique to those living with HIV - the loss of human touch. Persons living with HIV have talked of the intense sense of aloneness they feel when they are "treated like lepers", and only touched with a gloved hand. They comment on feeling like, and being treated like, a walking, talking germ. Whether it is fear of infection or simply lack of knowledge that prevent, caregivers or family members from touching a person living with HIV or AIDS, the results of not being touched can be emotionally devastating. An HIV positive man in Edmonton spoke of how he felt when his sister wouldn't hug him anymore or let his nephews sit on the sofa next to him:

"So much has changed in my life since I was diagnosed, but I never thought my family would change: change how they respond to me as a person they say they still love. I used to get a hug every time I came over for a visit, and the kids would be all over me ... it felt so welcoming. Now there is no hug at the door, and although they deny it, my nephews look scared when I'm around. And there's no more play. Babies die of failure to thrive when they don't get enough attention or human contact...well, it's killing me too."

Lovers, Family and Friends

Friends, lovers, spouses, parents and caregivers are all identified as persons who are affected by HIV. Although not infected, people who are affected by HIV are often immersed in the reality of living with the same stigma, isolation and fears that the HIV positive person does.

> "Ever after he greeted me with a hug. We used to joke that it was my assessment tool. From our hugs I could tell how strong he was. I could tell if he'd lost weight, if he had a fever, or if he was dehydrated. Most people are afraid of any physical contact with AIDS clients. But we all need to be touched and when we are deprived of physical contact, we crave it. "Skin hunger" can weaken a person, just like pneumonia." (Welcome Home: Stories from the Edmonton Home Care Program)

Partners or spouses must confront their own fears of infection, fear of death and questions around their own competency to provide care to a person who is dying. When the HIV positive partner is ill, the caregiver's work is exhausting, both physically and emotionally, and the knowledge that they are going to lose the person they care for the most in the world is devastating.

Parents and family members often become the caregivers for people who do not have a partner or spouse. Again, all the fears experienced by partners can be felt by parents or sisters and brothers. For many parents, the task of caring for a son or daughter who is dying is complicated by the strong sense that "children aren't supposed to die first."

In many cases, the parents of HIV positive persons will experience guilty feeling of having somehow been responsible for their child's lifestyle or sexual orientation. If they had previously rejected their son or daughter, the guilt is compounded. The stigma associated with HIV/AIDS also has a significant impact on the parents, often leading them to lie to their friends about the cause of their child's illness.

"It's far better to have the help of friends and neighbors to care for a son who is dying of "leukemia", than to be left alone with no support caring for a son who has AIDS." (father of an Edmonton person living with HIV).

Women

As discussed previously, the impact of HIV infection and facing the realities of a life-threatening diagnosis comes with an entire set of unique emotional and practical concerns for women, especially those with small children. Concern for the children often becomes greater than concern for their own health. One of the most pressing needs expressed by HIV positive women is that of child-care. When a single mother becomes ill and requires hospitalization, caregivers for her children must be found.

> "The biggest adjustment has been doing a will and that kind of stuff. Realizing I'm going to leave my kids behind... Most people don't think it is going to happen to them."
> (Alberta person living with HIV)

The intense emotional stress caused by insufficient child care has an extremely negative impact on the woman's immune system and general well-being. Often, women discharge themselves from hospital prematurely, to ensure that their children are cared for, and keeping up with the demands of caring for young children only adds to their fatigue. Planning for the future and finding someone to care for the children after her death is another major stressor for a single mother, especially if her parents are too old to take on the task of child-rearing.

Women who are HIV positive and caring for a family member (child, partner or spouse) who is also infected, tend to neglect their own health so that they can care for the other. Being the family caregiver is a traditional role for many women, and being HIV positive threatens their role in the family, as well as their own health. This double-barreled threat can result in denial of physical symptoms in an attempt to

maintain identity as the one who cares for and keeps the family together.

> "Support means showing you care. Treating you as a whole person. Listening to what I say and hearing what I need. The support group is supportive because it builds self-esteem and self-acceptance. But seeking support is taking a risk - a risk of being rejected or being misunderstood. My first attempt at getting support from an agency was really devastating. I wasn't heard at all. I felt very alone and without anywhere to turn - it felt like a dead end."
> (Edmonton person living with HIV)

Living in the Inner City

The psychosocial challenges confronted by HIV positive people in the inner city and by those with injection drug addictions are unique and complex.

In the inner city, acknowledging HIV status can mean exclusion from the community of people who have become their only source of support. As in the gay community, people in the inner city often adopt a family of choice - a group of people who provide them with the dignity that they have been denied elsewhere.

According to *Ending the Isolation* by Health Canada, "individuals who inject substances have the highest risk of contracting and transmitting HIV infection. The proportion of people whose risk factor for disease is injection drug use...is growing steadily. Drug use can create a pressured and impulsive lifestyle which does not encourage concern for safety and may itself be a co-factor for HIV infection. Once infected, the psychosocial consequences of HIV are more devastating than in other groups."

Ethno-cultural Challenges

Ethno-cultural uniqueness can compound the psychological impact of HIV infection. Culture, language or religion may act as a barrier to people getting the information they need, and complicate their abilities to access support.

In some cultures, attitudes towards sexuality, addictions and/or illness prevent individuals from accessing the information they need to protect their health. Often the educational materials needed are not available in the right language, or in a form the

individual can read. Although our society as a whole is far from accepting of homosexuality, it is totally rejected in some cultures. For persons living with HIV and who are also gay, disclosure of their diagnosis can mean expulsion from their cultural group entirely, and be emotionally devastating.

HIV is clearly a growing threat to the aboriginal peoples of Canada, and Edmonton is no exception.

A growing number of local Aboriginal people are known to be HIV positive. Many Aboriginal people will not seek out medical or social services, either as a result of previously experienced discrimination by the "system," or because of the cultural insensitivity of the services offered.

> "There's something really positive that comes from helping others...I think that becoming involved in the counselling program has helped me stay healthier, both physically and emotionally."
> (Peer Counsellor from Living Positive)

Culturally sensitive peer education and counselling strategies are being developed to address the needs – and recognize the strengths – of people who are considered "different" than the mainstream, and to support them as they confront the issues of HIV infection in their communities.

Getting Help

Reaching out and accessing support, whether in the form of an individual counsellor (peer or professional) or from a support group, is incredibly difficult for some people. For some, acknowledging that they need support is very difficult. For others, reaching out means admitting that they are getting sicker and losing the battle against the virus.

The value of both peer and professional counselling services has been acknowledged by numerous persons living with HIV/AIDS. In addition, support groups provide an opportunity to mutually share experiences and feelings in a supportive group environment.

There are several support groups in Edmonton, some designed for people living with the virus, others for people who are affected by HIV; partners, parents, and friends. The AIDS Network of Edmonton, and the University of Alberta Hospital offer professional counselling by psychologists and social workers. Living Positive, Alberta Society for Positive Women, and Feather of Hope all offer group and individual peer support and counselling. The Haemophiliac Society also accesses professional counselling for its members.

"In the old days it was measles, TB and smallpox. Now it's AIDS. Protect the People. Get involved." (Feather of Hope Aboriginal AIDS Prevention Society)

For persons who are unable to leave their homes due to the poor state of their health, counselling in the home can be provided by peer counsellors as well as by Clinical Social Workers from both the AIDS Network of Edmonton Society and the Home Care Program.

Appendix

Resources

Thirty-four envelopes covering a full range of topics areas related to HIV infection – from Abstinence to Workplace Issues. These envelopes were compiled by the resource staff at the AIDS Network, and they have agreed to let us reproduce them. A list of the contents is on the outside of each envelope.

AIDS Network 488-5742

•

Information for Professionals and Experienced Volunteers - HIV Antibody Testing

This booklet outlines the steps and content of HIV antibody pre- and post-test counselling, and includes client brochures. The package was developed by Alberta Health and additional copies are available at no cost. Alberta Health, Communications Branch, is located on the 18th Floor, 10025 Jasper Ave., Edmonton. They can be reached by phone at 427-7164 or by fax at 427-1577.

•

A Comprehensive Guide for the Care of Persons with HIV Disease. Module 1: Adults (Men, Women and Adolescents). Module 2: Infants, Children and Youth. Module 4: Palliative Care

This guide was prepared by the College of Family Physicians of Canada in 1993, and was funded by Health, Canada, AIDS Care and Treatment Unit. Written as a guide for physicians new to the care of HIV positive persons, it contains diagnostic and treatment algorithms which may be of interest or assistance to nurses involved in the care of persons living with HIV/AIDS. Additional copies can be obtained by calling the Canadian Public Health Association, National AIDS Clearinghouse at (613) 725-3769.

•

Modules addressing additional topics are being developed.

At Home with HIV

This brochure was produced by the Edmonton Board of Health (now Public Health Services), and is a straightforward, easy-to-read guide to Universal Precautions as they apply in the home. The brochure was designed for people who live with, work with or visit people who have HIV infection or AIDS. Copies of this brochure are available from the Public Health Services resource office. Call JoAnn Cooke at 482-9845.

•

Living with Dying - Dying at Home... An AIDS Care Team Resource Manual

Produced by the AIDS Committee of Toronto, this binder is filled with useful information for the informal and formal care provider alike. The purpose of the work is to guide people through the steps required to bring people together to act as an AIDS care team. From the initial steps involving setting up a care team, through to bereavement follow-up, this manual addresses most of the concerns and issues related to caring for an individual who is at the end-stage of AIDS. This binder is available at no cost from the National AIDS Clearinghouse, at (613) 725-3769.

•

Living Positive Society brochure

•

Feather of Hope Aboriginal AIDS Prevention Society brochure

Edmonton Home Care Program - HIV agency resource people

S.E. Network 496-1330
Angus Bates

S.W. Network 496-8445
Penny Parker, Sue Harris

N.E. Network 496-1320 or 496-1340
Anna Hanschar, Pat Dicks

N.W. Sturgeon Network 460-4731
St. Albert

To contact an HIV/AIDS Organization near you, see pp. 98-99 at the end of this appendix.

CDC Classification System for HIV Infection in Adolescents and Adults (>13 years)

These categories correspond to CD4 T-lymphocyte counts per microliter of blood, and guide clinical and therapeutic actions in the management of HIV-infected adolescents and adults. The revised HIV classification system also allows for the use of the percentage of CD4 T-lymphocyte cells.

HIV-infected persons should be classified based on existing guidelines for the medical management of HIV-infected persons. Thus, the lowest accurate, but not necessarily the most recent, CD4 T-lymphocyte count should be used for classification purposes.

Clinical Categories

The clinical categories of HIV infection are defined as follows:

Category A

Category A consists of one or more of the conditions listed below in an adolescent or adult (>13 years) with documented HIV infection. Conditions listed in Categories B and C must not have occurred. Conditions are:

- Asymptomatic HIV infection;
- Persistent generalized lymphadenopathy; and
- Acute (primary) HIV infection with acccompanying illness or history of acute HIV infection.

Category B

Category B consists of symptomatic conditions in an HIV-infected adolescent or adult that are not included among conditions listed in clinical Category C and that meet at least one of the following criteria:

a) the conditions are attributed to HIV infection or are indicative of a defect in cell-mediated immunity; or

b) the conditions are considered by physicians to have a clinical course or to require management that is complicated by HIV infection.

Examples of conditions in clinical Category B include, but are not limited to:
• Bacillary angiomatosis;
• Candidiasis, oropharyngeal (thrush);
• Candidiasis, vulvovaginal – persistent, frequent or poorly responsive to therapy;
• Cervical dysplasia (moderate or severe) /cervical carcinoma in situ;
• Consitutional symptoms, such as fever (38.5C) or diarrhea lasting more than one month;
• Hairy leukoplakia, oral;
• Herpes zoster (shingles), involving at least two distinct episodes or more than one dermatome;
• Idiopathic thrombocytopenia purpura;
• Listeriosis;
• Pelvic inflammatory disease, particularly if complicated by tubo-ovarian abscess; and
• Peripheral neuropathy

For classification purposes, Category B conditions take precedence over those in Category A. For example, someone previously treated for oral or persistent vaginal candidiasis (and who has not developed a Category C disease) but who is now asymptomatic, should be classified in clinical Category B.

Category C

For classification purposes, once a Category C condition has occurred, the person will remain in Category C. Category C includes the clinical conditions listed in the AIDS surveillance case definition of:
• Candidiasis of bronchi, trachea or lungs;
•Candidiasis, esophageal;
• Cervical cancer, invasive;
• Coccidioidomycosis, disseminated or extrapulmonary;
• Cryptococcosis, extrapulmonary;
• Cryptosporidiosis, chronic intestinal of more than one month duration;
• Cytomegalovirus disease (other than liver, spleen or nodes);
• Cytomegalovirus retinitis (with loss of vision);
• Encephalopathy, HIV-related;
• Herpes simplex, chron-

ic ulcers (more than one month duration);
• Histoplasmosis, disseminated or extrapulmonary;
• Isosporiasis, chronic intestinal (more than one month duration);
• Kaposi's sarcoma;
• Lymphoma, Burkitt's (or equivalent term);
• Lymphoma, immunoblasitic (or equivalent term);
• Lymphoma, primary of brain;
• Mycobacterium avium complex or M.y kansasii, disseminated or extrapulmonary;
• Mycobacterium tuberculosis, any site (pulmonary or extrapulmonary);
• Mycobacterium, other species or unidentified species, disseminated or extrapulmonary;
• Pneumocystis carinii pneumonia;
• Pneumonia, recurrent;
• Progressive multi-focal leukoencephalopathy;
• Salmonella septicemia, recurrent;
• Toxoplasmosis of brain; and
• Wasting syndrome due to HIV.

CDC Classification System for HIV Infection in Children (<13 years)

Class P-0
Indeterminate infection

Class P-1
Asymptomatic infection
• Subclass A. Normal immune function
• Subclass B. Abnormal immune function
• Subclass C. Immune function not tested

Class P-2
Symptomatic infection
• Subclass A. Nonspecific findings
• Subclass B. Progressive neurologic disease including HIV encephalopathy in the CDC surveillance definition for AIDS
• Subclass C. Lymphoid interstitial pneumonitis in the CDC surveillance definition for AIDS
• Subclass D. Secondary infectious diseases
Category D-1 Specified secondary infectious diseases in the CDC surveillance definition for AIDS

Category D-2 Recurrent serious bacterial infectionsin the CDC surveillance definition for AIDS
Category D-3 Other specified secondary infectious diseases
• Subclass E. Secondary cancers
Category E-1 Specified secondary cancers in the CDC surveillance definition for AIDS
Category E-2 Other cancers possibly secondary to HIV infection
• Subclass F. Other diseases possibly due to HIV infection

Coming to grips with a son's homosexuality – before it's too late

Ann Quindlen, The New York Times, reprinted in The Ottawa Citizen, April 13, 1987

When he went home last year he realized for the first time that he would be buried there, in the small gritty industrial town he had loathed for as long as he could remember. He looked out the window of his bedroom and saw the siding of the house next door and knew that he was trapped, as surely as if he had never left for the city.

Late one night, before he was to go back to his apartment, his father tried to have a conversation with him, halting and slow, about drug use and the damage it could do to your body. At that moment he understood that it would be more soothing to his parents to think he was a heroin addict than that he was a homosexual.

That is part of the story of a friend of mine. She went to his funeral not too long ago. The funeral home made the family pay extra to embalm him. Luckily, the local paper did not need to print the cause of death.

His parents' friends did not ask what killed him, and his parents never talked about it. He had AIDS. His parents had figured out at the same time that he was dying and that he slept with men. He tried to talk to them about his illness; he didn't want to discuss his homosexuality. That would have been too hard for them all.

Never have the lines between sex and death been so close, the chasm between parent and child so wide.

His parents hoped almost until the end that some nice girl would "cure" him. They even hinted broadly that my friend might be that nice girl. After the funeral, as she helped with the dishes in their small kitchen with the window onto the

backyard, she lost her temper at the subterfuge and said to his mother: "He was gay. Why is that more terrible that he is dead?" The mother did not speak, but raised her hands from the soapy water and held them up as though to ward off the words.

I suppose this is true of many parents. For some, it is simply that they think that homosexuality is against God, against nature, condemns their sons to hell.

For others, it is something else, something more difficult to put into words. It makes their children too different from them. We do not want our children to be too different – so different that they face social disapprobation and ostracism, so different that they die before we do. His parents did not know any homosexuals, or at least they did not believe that they did. His parents did not know what homosexuals were like.

They are like us. They are us. Isn't that true? And yet, there is a difference. Perhaps mothers sometimes have an easier time accepting this. After all, they must accept early on that there are profound sexual differences between them and their sons. Fathers think their boys will be basically like them. Sometimes they are. And sometimes, in a way that comes to mean so much, they are not.

I have thought of this a fair amount because I am the mother of sons. I have managed to convince myself that I love my children so much that nothing they could do would turn me against them, or away from them, that nothing would make me take their pictures off the bureau and hide them in a drawer.

A friend says I am fooling myself, that I would at least be disappointed and perhaps distressed if like his, my son's sexual orientation was not heterosexual. Maybe he's right.

There are some obvious reasons to feel that way. If the incidence of AIDS remains higher among

homosexuals that among heterosexuals, it would be one less thing they could die of. If social prejudices remain constant, it would be one less thing they could be ostracized for.

But this I think I know. I think I could live with having a son who is homosexual. But it would break my heart if he was homosexual and felt he could not tell me so, felt that I was not the kind of mother who could hear that particular truth. That is a kind of death, too, and it kills both your life and your child and all you have left after the funeral: the relationship that can live on inside you, if you have nurtured it.

In the days following the funeral, the mother of my friend's friend mourned the fact that she had known little of his life, had not wanted to know.

"I spent too much time worrying about what he was," she said. Not who. What. And it turned out that there was not enough time, not with almost daily obituaries of people barely three decades old, dead of a disease she had never heard of when she first wondered about the kind of friends her boy had and why he didn't date more.

It reminded me that often we take our sweet time dealing with things that we do not like about our children: the marriage we could not accept, the profession we disapproved of, the sexual orientation we may hate and fear.

Sometime we vow that we will never, ever accept these things. The stories my friend told me about the illness, the death, the funeral and, especially, about the parents reminded me that sometimes we do not have all the time we think to make our peace with who our children are.

It reminded me that never can last a long, long time. Perhaps much longer than we intended, deep in our hearts, when we first invoked its terrible endless power.

Edmonton has a chapter of PFlag - Parents, Families and Friends of Lesbians and Gays. Info/support lines (403) 462-5958, (403) 448-0173 VB 3524.

Some Recommended HIV/AIDS Materials

Books

For current/informative books please contact the AIDS Network Resource Centre at 488-5742.

ACT UP/New York Women and AIDS Book Group
1990 Women, AIDS and Activism. Boston, MA: South End Press

Archdiocese of Saint Paul and Minneapolis
1992 For Those We Love: A Spiritual Perspective on AIDS. Cleveland, Pilgrim Press

Balka, Christine and Andy Rose
1989 Twice Blessed on Being Lesbian or Gay and Jewish. Boston: Beacon Press

Bartlett, J. and A. Finkbeiner
1991 The Guide to Living with HIV Infection. John Hopkins University Press

Blake, Jeanne
1990 Risky Times: How to be AIDS Smart and Stay Healthy: A Guide for Teenagers. New York: Workman Publishing

Bonneau, Normand et al
1993 AIDS and Faith, Ottawa, Novalis

Callen, Michael
1990 Surviving AIDS. New York: Harper and Collins

Coyle, Susan L., Robert F. Boruch and Charles F. Turner (Eds.)
1991 Evaluating AIDS Prevention Programs Expanded Edition. National Academy Press: Washington Press

Gallo, Robert
1991 Virus Hunting: AIDS: Cancer and the Human Retrovirus: A Story of Scientific Discovery. Basic Books

Greggs, John, Sally ogers and David Goulds (Eds.)
1991 Simple Acts of Kindness: Volunteering in the Age of AIDS. United Hospital Foundation of New York

Hein, Karen and Teresa Foy Digeronimo
1991 AIDS: Trading Fears for Facts, A Guide for Young People. Consumes Union of the United States, Inc.: Yonkers, N.Y.

Illingworth, Patricia
1990 AIDS and the Good Society. London: Routledge

Jarvis, Debra
1990 HIV Positive Women Living with AIDS

Kaiser, Jon D, M.D.
1993. Immune Power: A Comprehensive Treatment Program for HIV. New York, St. Martin's Press

Klein, Michael (Ed.)
1989 Poets for Life: 76 Poets Respond to AIDS. New York: Crown Publishers

Kübler Ross, Elisabeth
1987 AIDS, The Ultimate Challenge. New York, Macmillan Publishing Company

Lapierre, Dominique
1990 Beyond Love. New York, Warner Books

McDonald, John R., Robert St. Pierre and Robert Shearer
1992 HIV-T: A Story Little Known, A Sourcebook for the Concerned. Members of the Canadian HIV+ Blood Transfused Community

McKenzie, Nancy F. (Ed.)
1991 The AIDS Reader: Social, Political, Ethical Issues. New York: Meridian Books

Monette, Paul
1988 Borrowed Time: An AIDS Memoir. New York: Avon Books
1991 Afterlife. New York: Crown Publishers
1991 Halfway Home. New York, Crown Publishers

Murphy, Sheila
1993. Healthy Eating Makes A Difference: A Food Resource Book for People Living With HIV. Ottawa - Health & Welfare Canada - Copies available at the National AIDS Clearing House (613) 725-3769.

Overall, Christine and William P. Zion
1991 Perspectives on AIDS Ethical and Social Issues. Toronto: Oxford University Press

Peiperl, Laurena
1992 Manual of HIV/AIDS Therapy

Pinsky, Laura and Paul Harding Douglass with Craig Metroka, M.D. PhD.
1992 The Essential HIV Handbook: The Treatment Fact Book. Pocket Books: New York, Toronto, London. 1230 Avenue of the Americas, new York, NY 10020. ISBN0-671-72528-9

Project Inform
1995. The HIV Drug Book. New York, Pocket Books

Rudd, Andrea and Darien Taylor (Eds.)
1992 Positive Women: Voices of Women Living With AIDS. Toronto, Ontario: Second Story Press.
ISBN 0-929005-30-9

de Solla Price, Mark
1995 Living Positively In a World with HIV/AIDS, New York, Avon Books

Shilts, Randy
1988 And the Band Played On: Politics, People and the AIDS Epidemic. Penguin Books

Siano, Nick
1993 No Time to Wait: A Complete Guide to Treating, Managing and Living with HIV Infection. New York, Bantam Books

Watstein, Sarah Barbara and Robert Anthony Laurich
1990 AIDS and Women: A Sourcebook. Phoenix Arizone: Oryx Press

Waxler-Morrison, Nancy, Joan Anderson and Elizabeth Richardson (Eds.)
1990 Cross-Cultural Caring: A Handbook for Health Professionals in Western Canada. University of British Columbia Bress, 6344 Memorial Road, Vancouver, B.C. V6T 1W5. ISBN 0-7748-0343-6

Whitehead, Mark & Brent Patterson
1993 Managing Your Health: A Guide for People Living With HIV or AIDS. Toronto, CATIE (Revised)

Health and Welfare Canada
1990 Infection Control Guidelines and Precaution Techniques. Health Services Directorate, Health Services and Promotion Branch and the Bureau of Communicable Disease Epidemiology. Health Protection Branch.

Alberta Health

Available from the Provincial AIDS Program are:

- HIV prevention pamphlets/posters

- HIV/AIDS care, treatment and support pamphlets, ie. the LET'S TALK HIV series is available in print and on audiotape.

- Research and evaluation reports regarding HIV/AIDS prevention programming.

To obtain resources call 427-0836

Journals / Periodicals

AIDS Patient Care

AIDS Prevention and Education

FOCUS, A Guide to AIDS Research and Counselling Published by the AIDS Health Project affiliated with the University of California, San Francisco. Box 0884, San Francisco, CA 94143-0884. (415) 476-6430. Back issues $3.00

Journeymen: The Bold New Quarterly for Men

Project Inform (PI) Perspective Project Inform, 347 Delores, Suite 301, San Francisco, CA 94110. 1-800-822-7422

Positively Aware: The Monthly Journal of the Test Positive Aware Network 1340 West Irving Park, Box 259 Chicago, Illinois 60613. (312) 472-6397 or fax (312) 472-7505

POZ, published monthly by Strubco Inc., 349 West 12 Street, New York, N.Y. 10014

Organizations and Institutional Publishers

AIDS Committee of Toronto Resource Centre

AIDS Network of Edmonton
1991 *Guide to the Resource Centre*

American Foundation for AIDS Research

Canadian AIDS Society (CAS)
Safer Sex Guidelines: A Resource Document for Educators and Counsellors. Report from the CAS Consultation on Safer Sex, March, 1988. Recommend Update.

Canadian Public Health Association, National AIDS Clearinghouse
1987 Report on AIDS/STD Education for Youth October.
Canadian AIDS News: The New Facts of Life
All Canadian Catalogue
(613) 725-3769

The Centre for Family Life Education
1989 Teaching Safer Sex by Peggy Brick with C. Charlton, H. Kunins, and S. Brown, Centre for Family Life Education, 575 Main Street, Hackensack, New Jersey 07601
(201) 489-1265

Community AIDS Treatment and Information Exchange (CATIE)
Treatment Update (TU)/Traitement Sida (An information resource for persons considering experimental treatment and/or therapies for HIV/AIDS related illnesses). ISSN 11817186. Subscriptions: John Gunter, Suite 324, 517 College Street, Toronto, ON, M6G 4A2. (416) 944-1916. Canadian subscriptions: $15 individual, $25 institutions. Back issues $1.50 each

The Cutting Edge
Publisher on AIDS and other publications.
Box 392, Fremont, CA. 94537

Edmonton Interagency Council on AIDS
Directory

ETR Associates
PO Box 1830, Santa Cruz, CA 95061-1830. (408) 438-4060 or 1-800-321-4407. Produces material on HIV/AIDS prevention

The Institute for the Advanced Study of Human Sexuality

Les Editions CommuniquElles
Canadian Women and AIDS: Beyond the Statistics. 3585, rue St. Urbain, Montreal, Quebec, H2X 2N6. (514) 844-1761, or fax (514) 842-1067

Public Health Services, Capital Health Authority (formerly Edmonton Board of Health)
AIDS Prevention and Control Directory, 1989

The Sexuality Library and The Sexuality Library Jr. Anniversary Catalogue, 1210 Valencia Street, San Francisco, CA 94119. (415) 550-7399 or fax (415) 550-8495. Including, for example, Bi Any Other Name: Bisexual People Speak Out, Loraine Hutchins and Lani Kaahumanu (Eds.), 1991 (#BB636).
The Bisexual Spouse: Different Dimensions in Human Sexuality, Ivan Hill (Ed.), 1987 (#BB285).
Bisexuality: A Reader and Source Book, Thomas Geller (Ed.), 1990 (#BB400)

SIECUS 1991
Winning the Battle: Developing Support for Sexuality and AIDS Education by Debra W. Haffner and Diane de Mauro. Sex Information and Education Council of the U.S. , 130 West 42 Street, Suite 2500, New York, NY 10036. (212) 819-9770 or fax (212) 819-9776

Women and AIDS Strategies for the Future. Panel Proceedings, CIDA World AIDS Day Series. Women in Development with the Health and Program Directorates. December 6, 1990. Hull, Quebec.

Women's Project/Comite ELLES
A program of the AIDS Committee of Ottawa, run by women and funded by Health Canada. 267 Dalhousie Street, Ottawa, Ontario, K1N 7E3. (613) 238-5014 or fax (613)238-3425. Series: *Good News/Bad News, Women and AIDS, Health and HIV,. Safety and Sex* (Some comforting safer sex information for women who have sex with men), and more

World Health Organization
1989 Monitoring of National AIDS Prevention and Control Programs, Guiding Principles. WHO AIDS Series 4, Geneva

1989 Paris Declaration on Women, Mothers, Children and Global AIDS. Global Program on AIDS

1990 Guidelines for Counselling about HIV Infection and Disease. WHO AIDS Series 8, Geneva

1990 Guidelines on AIDS and First Aid in the Workplace. WHO AIDS Series 7, Geneva.

1990 AIDS: A Special Threat to Women. WHO November-December

Newsletters

AIDS Network of Edmonton
V.I.P. News

AIDS Treatment News
Published 2 times per month. John S. James, PO Box 411256, San Francisca, CA 94141. (415) 255-0588

Metropolitan Community Church
Alert

Boston Women's Health Collective
Healthsharing

Videos

AIDS Network of Edmonton
1991 *Guide to the Resource Centre*

Canadian Public Health Association
All Canadian Catalogue

Films for the Humanities and Sciences
Items, Catalogues and listings on Sex Education and HIV/AIDS Education on video. PO Box 1051, Fort Erie, Ontario, L2A 5N8. 1-800-257-5126

Instructional Technology Centre, University of Alberta
Contact Katie Campbell-Bonar, 492-3667

Provincial Film Library
11510 Kingsway Avenue, 2nd Floor, Queen's Printer Building, Edmonton, Alberta 427-4381

Sunburst Catalogue of Videos (for grades 2-12 and up) 1992-93 Health Home and Family Living, Sunburst Comunications, 920 Mercer Street, Windsor, Ontario. 1-800-431-1934

Caring Together Resources

1994 The Living Resource. An experimental reflection on living with HIV in Edmonton. AIDS Network of Edmonton 488-5742

1994 The Resource Kit (Think Positive). An inservice tool for service providers to sensitize staff to experiences of positive individuals. AIDS Network of Edmonton 488-5742

1994 Train the Trainer. A skill development course for training others in the community. AIDS Network of Edmonton 488-5742

Finding AIDS/HIV Resources Online

Here are some resources on the World Wide Web. Use them to find many more links to other and new sites.

AIDS Resource List
http://www.teleport.com/~celinec/aids.shtml

Einet Galaxy's AIDS and HIV Page
http://galaxy.einet/galaxy/community/health/diseases/aids-and-hiv.html

HIV Net/Gena Information Server
http://hivnet.org/

The Red Ribbon Net
http://worldclass.com/redribbon/

Project Inform
http://www.hivnet.org/inform-www/index.html

Centers for Disease Control and Prevention
http://cdcnac.aspensys.com:86/

Canadian HIV Trials Network
- contains links to other Canadian sites
http://unixg.ubc.ca:780/~fortin/mancel.html

AIDS Treatment News
http://www.tcp.com:8000/qrd/www/aids.bbc/periodicals_atn.html

HIV Info Web
http://www.jri.org/infoweb/

Other HIV Resources in Alberta

AIDS/STD Toll Free Information Line
Confidential Information
24 hours a day — Ph: 1-800-772-2437

Community AIDS Organizations

Alberta Health, Provincial AIDS Program
9th Floor, 10025 Jasper Avenue — Ph: (403) 427-0836
Edmonton, Alberta T5J 2N3 — F: (403) 422-6663

AIDS Calgary Awareness Association
#300, 1021 - 10th Avenue, S.W. — Ph: (403) 228-0198
Calgary, Alberta T2R 0B7 — F: (403) 229-2077

AIDS Network Edmonton
201, 11456 Jasper Avenue — Ph: (403) 488-5742
Edmonton, Alberta T5K 0M1 — F: (403) 488-3735

Feather of Hope Aboriginal
AIDS Prevention Society (FOHAAPS)
201, 11456 Jasper Avenue — Ph: (403) 488-5742
Edmonton, Alberta T5K 0M1 — F: (403) 488-3735
Toll Free Number — 1-800-256-0459

Living Positive
201, 11456 Jasper Avenue — Ph: (403) 488-5742
Edmonton, Alberta T5K 0M1 — F: (403) 488-3735

AIDS: A Positive Coordinated
Community Response Society of Jasper
Box 1090 — Ph: (403) 852-5274
Jasper, Alberta T0E 1E0 — F: (403) 852-5274

Banff Regional AIDS Committee
Box 219, Suite 5233 — Ph: (403) 762-0690
Banff, Alberta T0L 0C0 — F: (403) 762-2602

Central Alberta AIDS Network Society
4935 - 51 Street — Ph: (403) 346-8858/59
Red Deer, Alberta T4N 2A8 — F: (403) 346-2352

Foothills AIDS Awareness Society
Box 758
Okotoks, Alberta T0L 1T0
Ph: (403) 938-4911
F: (403) 938-2783

Interfaith Association on AIDS
#302, 11745 Jasper Avenue
Edmonton, Alberta T5K 0N5
Ph: (403) 448-1768
F: (403) 488-3735

Lethbridge AIDS Connection
421, 515 - 7th Street South
Lethbridge, Alberta T1J 2G8
Ph: (403) 328-8186
F: (403) 328-8564

South Peace AIDS Council
Box 902, 9931B - 100 Avenue
Grande Prairie, Alberta T8V 3Y1
Ph: (403) 538-3388
F: (403) 538-3368

Clinics

Northern Alberta HIV Clinic
Department of Medicine
2E4.11 MacKenzie Health Centre
Edmonton, Alberta T6B 2B7
Ph: (403) 492-8035
F: (403) 492-7137

Southern Alberta HIV Clinic
Health Sciences Centre, University of Calgary
3330 Hospital Drive, N.W.
Calgary, Alberta T2N 4N1
Ph: (403) 670-2480
F: (403) 270-8514

Housing

Society for Housing AIDS Restricted Persons (SHARP)
223 - 12th Avenue, S.W.
Calgary, Alberta T2R 0G9
Ph: (403) 263-8084

Kairos House
c/o Catholic Social Services
8815 - 99 Street
Edmonton, Alberta T6E 3V3
Ph: (403) 432-1137
F: (403) 439-3154

Notes

Notes

Notes

Notes

Notes

Notes

Notes